UNIVERSITY OF ALBERTA

THE EXPERIENCE OF WOMEN WHO UNDERGO HYSTERECTOMY

BY

MARIE-ANDREE CHASSE

©

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA

SPRING 1990

National Library of Canada
Bibliothèque nationale du Canada

Canadian Theses Service
Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

ISBN 0-315-60356-9

NL-339 (r. 88/04) c

Canada

THE UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: MARIE-ANDRÉE CHASSÉ

TITLE OF THESIS: THE EXPERIENCE OF WOMEN WHO UNDERGO HYSTERECTOMY

DEGREE: MASTER OF NURSING

YEAR THIS DEGREE GRANTED: SPRING 1990

Permission is hereby granted to the UNIVERSITY OF ALBERTA LIBRARY to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

Marie-Andrée Chassé
(Student's signature)

21 Grant St., Apt 20
Moncton, N-B
E1A 3R3
(Student's permanent address)

Date: March 7 1990

THE UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE EXPERIENCE OF WOMEN WHO UNDERGO HYSTERECTOMY submitted by MARIE-ANDRÉE CHASSÉ in partial fulfillment of the requirements for the degree of MASTER OF NURSING.

Janice M. Morse
.....
Supervisor

.....

.....

Date: March 5 1990

ABSTRACT

The purpose of this study was to examine the experiences of women who undergo a hysterectomy. A purposeful nonprobability sample consisted of 10 hysterectomy patients between the ages of 24 to 39 years of age, interviewed at one month and at three months postoperatively. Data were collected by means of unstructured tape-recorded interviews and detailed fieldnotes.

A grounded theory approach was used as the informant's subjective knowledge and understanding of the experience of undergoing a hysterectomy was the information sought. The systematic analysis of interview transcriptions yielded common categories which were linked together. The emerging categories and their linkages were substantiated through additional data collection, and were confirmed and validated by the informants. The result of this investigation is a theory which describes how women resolve and adjust to the experience of undergoing a hysterectomy. A variety of strategies such as theoretical sampling and a constant comparative analysis between informants' responses were implemented by the investigator to enhance the reliability and validity of the study.

The findings of this study indicate that the experience of women, who undergo a hysterectomy, is a process which comprises three emergent stages: the disruption of the body, the struggle to preserve wholeness, and the recovery. As the individual progresses through each stage, she attempts to establish boundaries of normality. The basic social process of *Establishing Boundaries of Normality* involves incorporating what is unknown into that which is known, ordinary, and familiar. This process enables hysterectomy patients to understand and remain in control of bodily changes, and to protect their self-esteem. Hysterectomy patients establish boundaries of normality by developing a frame of reference which gives coherence to their experience of bodily changes. Women continuously revise their frame of reference as they progress through each stage of the

hysterectomy experience. The adjustment and resolution of the experience of undergoing a hysterectomy is contingent upon the successful establishment of boundaries of normality.

ACKNOWLEDGMENTS

I would like to acknowledge the assistance of many people who have contributed to the process of completing this research.

I am extremely grateful to my thesis supervisor, Dr. Jan Morse, for her enthusiasm, expertise and generosity. In particular, I am extremely grateful for her perceptiveness and guidance throughout the course of this research. Her dedication to nursing research has provided me with a true source of inspiration.

I also wish to thank my co-supervisor, Dr. Vangie Bergum, for her caring and support. Her insightful questions stimulated my thinking and her encouragement was greatly appreciated. I also wish to thank Dr. David Cumming for his interest and valuable suggestions during the course of this research.

I wish to recognize my family, friends, and colleagues who have stood by me and offered their support. In particular, I would like to thank Luc Therrien, who spent countless hours typing this thesis, and who offered me an unending source of support and encouragement.

Finally, I am indebted to those women who talked to me about their experiences and who patiently answered my questions. The knowledge that I have gained from these women is invaluable.

Financial assistance for this project was provided in part by the Alberta Foundation for Nursing Research and the Alberta Association of Registered Nurses.

TABLE OF CONTENTS

CHAPTER PAGE

I. INTRODUCTION 1

Statement of the Problem 1

Purpose and Rationale 2

The Research Question 3

II. LITERATURE REVIEW 4

Psycho-social Aspects of the Hysterectomy Experience 4

Bodily Changes Following Hysterectomy 9

Summary 11

III. METHOD 12

Grounded Theory 12

Sample 13

Data Collection 14

Data Analysis 17

Reliability and Validity 18

Ethical Considerations 20

IV. FINDINGS 22

Establishing the Boundaries of Normality 22

Stage I: The Disruption of the Body 26

Experiencing the Symptoms 26

Perceiving a Health Problem 30

Learning to Read the Body 31
Exploring/Recognizing Triggers 34
Cycle Triggers 34
Activity Triggers 36
Event Triggers 37
Trigger Combinations 38
Evaluation of the Illness Experience 39
Negotiating the Medical Management of the Condition 46
The Hysterectomy Decision-making 49
Stage II: The Struggle to Preserve Wholeness 52
Managing the Separation 52
Becoming a Patient 53
Observing the Changes 62
Stage III: The Recovery 64
Adjusting to Changes 64
Resuming Sexual Activities 68
Coming to Terms with the Hysterectomy 70

V. DISCUSSION 74
Discussion of Research Method 74
Data Collection 74
Limitations 76
Discussion of Findings 76
Establishing the Boundaries of Normality 76
The Disruption of the Body 79
The Hysterectomy Decision-Making Process 86
The Struggle to Preserve Wholeness 87

The Recovery 91
Coming to Terms with the Hysterectomy 92
Implications for Nursing Practice 94
Implications for Nursing Research 98
Propositional Statements 98

VI. SUMMARY AND CONCLUSIONS 101

REFERENCES 104

APPENDIX 111

LIST OF TABLES

Table		Page
1	Biographical Characteristics of the Informants	15

LIST OF FIGURES

Figure	Title	page
1	The Experience of Women who Undergo a Hysterectomy	23
2	Establishing the Boundaries of Normality	25
3	Descriptors of Pain and Bleeding	27
4	Learning to Read the Body	35
5	Influence of Significant Others on Women's Coping and View of Illness	41
6	Influence of Spouse and Physicians on Women's Coping and View of Illness	45
7	Women's Perceptions of the Patient Role	55
8	Women's Perceptions of the Hysterectomy Experience	71

I. INTRODUCTION

Because of its fundamental role in reproduction, many social and personal values surround the uterus. Several hypotheses have been developed over the years which attribute a variety of functions to this organ, for example, the notion that "women are ruled by their reproductive organs" (Webb, 1987) and, although largely untested, these hypotheses attest to the importance and social significance of the uterus (see, Ehrenreich & English, 1973a). In light of this situation, it is understandable that the removal of the uterus is an issue of concern, debate and controversy. Recently published popular and professional works clearly illustrate the interest generated by this subject (Alix, 1986; Ananth, 1983; Morgan, 1985; Nadelson, Notman, & Ellis, 1983; Stanfill, 1982).

Currently, a hysterectomy is one of the most frequently performed surgical procedures in North America (Roos, 1984). In addition, it has been widely recognized that the prevalence of this operation is increasing (Dyck et al., 1977; Morgan, 1985; Wijma, Kauer, & Janssens, 1984). For example, the numbers and rates of hysterectomies in the United States rose by 25% between 1971 and 1975 (Easterday, Grimes, & Riggs, 1983). Furthermore, this rising prevalence has also been noted to be more significant for women under 45 years of age (Crowe, Sunley, & Sukenik, 1984; Dicker et al., 1982). Therefore, it is well established from these findings that many women who undergo hysterectomy do so during their reproductive years.

Statement of the Problem

A variety of aspects pertaining to the hysterectomy experience have been studied. In recent years, investigations related to particular physical consequences have generated a greater understanding of some bodily changes experienced after hysterectomy (Cohen, Hollingsworth, & Rubin, 1989). As a result, there have been improvements made in the control of complications such as postoperative infections, and in the relief of particular symptoms such as hot flushes. Despite these advances, it has been observed that there is

much that is yet to be understood about the uterus and the bodily changes experienced following a hysterectomy (Zussman, Zussman, Sunley, & Bjornson, 1981).

Several investigators have focused on exploring a number of psycho-social aspects of the hysterectomy phenomenon. For example, the recovery from hysterectomy is an area which has been extensively studied in terms of the occurrence of particular psychological changes, such as the incidence of depression (Barker, 1968; Richards, 1973; Gath, Cooper, & Day, 1982) and sexual problems (Dennerstein, Wood, & Burrows, 1977; Seibel, Freeman, & Graves, 1980). Although numerous, these research endeavors have yielded few advances as there is little consistency in the findings of these studies. Furthermore, these researchers have generally ignored women's own perceptions of their experience of a hysterectomy.

In contrast, a small body of research, characterized by a holistic perspective of inquiry, and exploring aspects such as social support and coping during the recovery from hysterectomy has yielded a greater understanding of this phenomenon (Gould & Wilson-Barnett, 1985; Webb, 1986; Webb & Wilson-Barnett, 1983a, 1983b). These investigations have provided insights into some women's perceptions of this experience, their needs during the recovery period, as well as information pertaining to the context in which they live their lives.

Generally, the existing knowledge base concerning hysterectomy patients offers a fragmented understanding of the experience of undergoing a hysterectomy as no firm conclusions can be drawn from current research findings. This situation is problematic for health professionals because effective and holistic care can only be based on a sound and complete understanding of this experience. Therefore, a clear understanding of the experience of women who undergo a hysterectomy must be attained in order to effectively assist and support these patients.

Purpose and Rationale

Nurses are concerned with individuals in a variety of health states and in those

processes which are a part of human experiences (Fugate-Woods, 1982). In addition, nurses have been acknowledged as the health practitioners who must play a special role in helping hysterectomy patients (Webb, 1987). However, research findings suggest that nurses fail to adequately inform and support these women (Krueger et al, 1979; Webb & Wilson-Barnett, 1983a). Therefore, in order to formulate effective and holistic strategies of care for hysterectomy patients, nurses must first seek to develop an understanding of what it is like to undergo a hysterectomy since little is known about these women's perceptions, needs, and the context in which they live their lives.

The Research Question

The central question that guided this investigation was:

"What are the experiences of women who undergo a hysterectomy?"

Subquestions also addressed in this study were:

1. What are the physical and psycho-social issues that women attempt to resolve?
2. What are the strategies that women use to resolve these issues?
3. What are the social and personal factors which influence the process of undergoing a hysterectomy?

II. LITERATURE REVIEW

Women who undergo a hysterectomy have been the subject of many investigations. Although numerous, these research endeavors have not generated a clear understanding of the hysterectomy experience. Most investigators have, to date, examined particular aspects of this phenomenon, while few have attempted to explore and describe the experience of a hysterectomy in its entirety. Because of the prevalence of a reductionistic perspective of inquiry, the knowledge base concerning women who undergo a hysterectomy remains fragmented and incomplete. The purpose of the following chapter is to review the literature pertaining to hysterectomy patients and to demonstrate the need for further investigation in this area.

The literature discussed in this chapter is categorized into two groups. The first category comprises studies of various psycho-social aspects of the hysterectomy experience as well as other works addressing the treatment and care of these patients. The second category regroups investigations and clinical papers which focus on the bodily changes experienced after hysterectomy.

Psycho-social Aspects of the Hysterectomy Experience

Most of the early studies of hysterectomy patients suggest that this surgery can lead to a number of negative psychological consequences. Lindemann (1941) investigated the occurrence of psychiatric problems following pelvic operations in women. He interviewed 40 women preoperatively and postoperatively in order to determine whether the amount of anxiety experienced before surgery was related to the occurrence of psychiatric symptoms during the recovery period. The subjects in this study had undergone surgery in the upper abdominal cavity or in the pelvic region. In comparing these two groups, Lindemann observed a type of psychiatric reaction similar to a state of agitated depression in 13 of the 40 patients. This reaction occurred twice as often in those women who had had pelvic operations. He also identified that the most definite indication for postoperative depressive

symptoms was a history of previous depression in a person undergoing a pelvic operation. Although frequently cited as one the leading researchers in the area of hysterectomy and depression, it is noted that Lindemann failed to specify if any of the 13 women who presented with depression had, in fact, undergone a hysterectomy. Furthermore, no data were provided as to the context surrounding this reaction.

Later researchers in this area have supported the notion that a history of depression is a significant indication for depressive reactions during the recovery from hysterectomy (Barker, 1968; Melody, 1962; Richards,1973). Furthermore, these investigators also reported a high incidence of postoperative depression and revealed additional factors which may contribute to the occurrence of this condition. These factors include: (a) the absence of gynecological pathology at operation, (b) a relatively young age, and (c) a history of marital problems, and (d) sexual problems. Among these studies, Barker's investigation is considered to be methodologically sounder than the others since it included adequate numbers of subjects, an appropriate control group, and statistical analysis of the results. However, a contradiction emerges when Barker's and Richards' conclusions are examined as they strongly suggest that depression may be a primary sequela of the hysterectomy procedure. This particular inference is viewed to be incongruent with their findings since preoperative factors contributing to the occurrence of depression were revealed in these investigations. Melody's discussion differs from that of these two researchers since he observed that the depressive reactions, occurring during the recovery period, seemed clearly precipitated by a traumatic social experience where the women perceived themselves as rejected and devalued by someone important to them. Some researchers have attempted to determine whether hysterectomy by itself leads to depression. Although these investigators noted a high incidence of postoperative depression, they failed to statistically relate this condition to the surgical event and discovered, instead, a strong relationship between depressive reactions and preoperative psychiatric problems (Gath et al., 1982; Moore & Tolley, 1976). In spite of a lack of conclusive evidence, the idea that depression

is a primary consequence of a hysterectomy persists in recent works pertaining to the treatment and care of women (Ananth, 1983; Derogatis, 1980; Nadelson et al., 1983).

A second controversial aspect of this literature is the purported high incidence of depression following hysterectomy. In contrast to the studies reviewed thus far, some investigators have reported from 70% to 90% of the women in their samples improved markedly in mood, energy, and physical health during the months following their hysterectomy (Ackner, 1960; Lalinec-Michaud & Engelsmann, 1984; Martin, Roberts, & Clayton, 1980; Richards, 1978). In addition, others have found no significant differences in relation to mood disturbance when hysterectomy patients were compared with groups of women recovering from procedures such as cholecystectomy, pelvic radiotherapy, and tubal ligation (Meikle, Brody, & Pysh, 1977; Seibel et al., 1980).

In a much cited psychoanalytical work, Drellich and Bieber (1958) reported that most of the women in their sample experienced a diffuse nonspecific anxiety following hysterectomy and expressed spontaneous regret over the loss of their childbearing ability. They also found that "some patients denied apprehension over the loss of their reproductive organs and some seemed to consciously welcome the operation, but this was often a denial of intolerable feelings of impending loss" (p.323). Unlike Lindemann (1941), these researchers did not report a high incidence of depression. Based on preoperative and postoperative interviews with 23 women undergoing hysterectomy for benign or malignant disease, they suggested that the uterus is a valued symbol of femininity and that its loss poses a threat to the female identity. Although interesting, this conclusion must be viewed with caution as it implies that a woman's main concern rests on the uterus alone and not on the fact that she may have a malignancy.

Patterson and Craig (1963) interviewed 100 posthysterectomy patients in order to obtain their reactions regarding their surgery. These informants differed strikingly from those of Drellich and Bieber (1958) in that none had undergone hysterectomy for a malignancy. These researchers were particularly interested in detecting possible changes in

self-concept, derogatory responses of relatives, changes in erotic drive along with discontent and depression. They found that most of the women in their sample did not perceive their female identity as threatened, and were contented with sterilization. They also noted that these women saw themselves not as mutilated, but whole and healthy. In addition, none of these informants complained of derogatory remarks from their husbands or relatives, and none reported more sexual problems than prior to the operation. These findings suggested to them that the male concern about castration may have led to the belief that women must think along the same lines. Later investigations have yielded similar results which further challenge the notion that a hysterectomy is usually a blow to a woman's concept of self (Cosper, Fuller, & Robinson, 1978; Hampton & Tarnasky, 1974; Kaltreider, Wallace, & Horowitz, 1979; Webb & Wilson-Barnett, 1983b).

As with self-concept, sexual functioning is also an aspect of this literature marked by controversy. It has been suggested that sexual functioning deteriorates significantly following a hysterectomy and that this problem may seriously compromise a marital relationship (Chynoweth, 1973; Dennerstein et al., 1977; Sewell & Edwards, 1979). In contrast, other investigators have reported no significant change in sexual function (Gath et al., 1982; Martin et al., 1980; Seibel et al., 1980). Bernhard's (1986) review of studies of sexuality and hysterectomy describes a number of problems related to methods, definition of terms, instruments and procedures as well as sampling approaches which may account for the discrepancy in results. In addition to these issues, it is noted that a majority of researchers assume that the extent of women's sexual experience is to be able to have intercourse. This assumption clearly underlies most definitions of the concept of sexual functioning and also emerges in the means utilized to measure this variable. The evident lack of acknowledgement of the multidimensional nature of women's sexuality represents, perhaps, the most basic problem of this body of research as it results in a limited and often inappropriate measurement of this concept.

Although many contradictions exist in clinical papers and in studies of the psycho-

social aspects of the hysterectomy phenomenon, health professionals and investigators alike emphasize the importance of supporting and informing women throughout this experience (Drummond & Field, 1984; Stanfill, 1982; Kaltreider et al., 1979; Lalinec-Michaud & Engelsmann, 1985). In recent years, attention has been given to the study of the support and information provided to hysterectomy patients. The findings of these investigations suggest that social support and meaningful information enhance women's ability to cope with their situation and adjust to their bodily changes (Webb, 1986; Webb & Wilson-Barnett, 1983a, 1983b). These investigators found that hysterectomy patients perceived the assistance provided during their convalescence as helpful only when it was given in ways which allowed them to control their own recovery. They reported that discouragement from being active during convalescence was a source of frustration and was viewed as unhelpful by these women. In a similar manner, unrealistic or joking forecasts about recovery often resulted in guilt and resentment when women's progress fell short of predictions. Furthermore, they noted that informants were critical of the information received from health professionals as it often consisted of general advice which left them with little knowledge to help them enhance their recovery and judge their progress. Webb (1986) suggested that full-time housewives may be particularly at risk of not receiving the assistance they require because of their relative isolation from other sources of support. Despite the fact that the majority of the women in these studies made a good recovery both physically and emotionally, these investigators found that the information provided by health professionals and the social support of partners, families and friends were in many instances low in quality and quantity.

A number of clinicians have proposed guidelines and interventions in order to adequately support and inform hysterectomy patients (Ananth, 1983; Drummond & Field, 1984; Stanfill, 1982; Steele & Goodwin, 1975). As the clinical experience of these health professionals represents the primary basis from which these criteria emerge, this work is rich in breadth and depth. However, it must be recognized that this particular body of

literature is lacking in systematic study and that the effectiveness of these measures remains unknown. Only three studies have been conducted to establish the level of effectiveness of a small number of interventions. These researchers report modest psychologic improvements for strategies which include: (a) providing a pamphlet which explains the hysterectomy procedure and describes the bodily changes resulting from it (Jackson, 1979), (b) assisting patients to enhance their cognitive coping skills (Ridgeway & Mathews, 1982), and (c) relaxation training (Lobb, Shannon, Recer, & Allen, 1984). Although interesting, the findings of these studies must be viewed with caution since they vary in method and rigor.

The research literature pertaining to the psycho-social aspects of the hysterectomy experience is characterized by contradictions and potential sources of invalidity which result in a limited and fragmented understanding of this phenomenon. Furthermore, it is apparent that a majority of investigators fail to recognize the perceptions of hysterectomy patients as a source of insight and often rely on a variety of unsubstantiated assumptions to guide their data collection and analysis. The work of Webb (1986), and of Webb and Wilson-Barnett (1983a,1983b) represent, perhaps, exceptions to this situation because of their thoroughness in reporting women's perceptions of their hysterectomy experience. It is clearly evident that more research endeavors which precisely describe women's perceptions are required as these could generate a more holistic and complete understanding of this experience.

Bodily Changes Following Hysterectomy

It has been documented that a number of symptoms may be experienced following a hysterectomy (Alix, 1986; Crowe et al., 1984; Morgan, 1985). Hot flushes, changes in libido, vaginal dryness, urinary frequency, fatigue, headaches, insomnia, anorexia, constipation and dizziness are examples of symptoms that have been reported for some women at various times during the recovery period (Gould & Wilson-Barnett, 1985; Richards, 1974; Roos, 1984; Zervos & Papaloucas, 1972). Generally, there is little in the

literature describing the factors which give rise to the majority of these bodily changes and the context which surrounds their occurrence.

Some authors have postulated that the cervix and uterus may be anatomical triggers of orgasm and that the removal of these structures may be partly responsible for a loss of libido (Zussman et al., 1981). Although interesting, there is currently no empirical evidence to substantiate these claims. Furthermore, no knowledge exists to explain why a majority of women experience no changes in libido following a hysterectomy.

In contrast, there is evidence to suggest that some physical symptoms may be related to hormonal changes. Richards (1974) reported that 39 of the 56 women he investigated experienced hot flushes after hysterectomy and that 19 of these patients were under 45 years of age. He also noted no clear relationship between hot flushes and oophorectomy, but found that this symptom, along with insomnia and urinary frequency, improved when oral estrogens were administered. Furthermore, he observed that decreased libido was sometimes helped by estrogen therapy. From these findings, he postulated that an endocrine imbalance is produced by the removal of the uterus itself. Zussman et al. (1981) critically analyzed the literature pertaining to this hypothesis and found that deductive research methods have failed to provide conclusive evidence to support this claim, although advances in endocrinology may tentatively suggest a hormonal basis for some physical symptoms as evidenced by the relief of loss of libido through estradiol/testosterone implants.

Clinicians and researchers appear to recognize that bodily changes may be anatomical or hormonal in origin, but a majority of them seem to emphasize the idea that most of these symptoms are psychologically based despite the fact that no more conclusive evidence exists in support of the psychogenesis theory (Zussman et al., 1981). The work of Ananth (1983) on sexual difficulties after hysterectomy as well as a study by Zervos and Papaloucas (1972) on psychosomatic disturbances following hysterectomy illustrate the prevalence of the psychogenesis theory in recent works.

To date, there has been little effort on the part of investigators to explore and describe the bodily changes experienced after hysterectomy from the patient's viewpoint. Consequently, there is little knowledge available about how patients perceive their bodily changes, the adjustment strategies that they utilize, as well as the social situations which impede or facilitate their adjustment. Clearly, it must be recognized that an understanding of how hysterectomy patients view, react, and adjust to these changes is required as this knowledge would assist nurses in developing therapeutic interventions to effectively support and inform these women.

Summary

This review of the hysterectomy literature reveals an incongruent picture regarding the impact of this surgery. Improvement and deterioration in psychological functioning and physical well-being have been reported to occur following this surgery. Generally, the variations in women's psychological and physical responses are poorly understood. Furthermore, the studies conducted in this area are fraught with conceptual and methodological problems, and tend to ignore the hysterectomy patient as a source of insight. Although the investigations and clinical papers cited in this review do provide some information regarding particular aspects of the hysterectomy experience, they represent a fragmented body of knowledge which does not contain the necessary information to assist health professionals in elaborating sound interventions to effectively support these women. In light of this situation, it seems important at this time to consider the examination of the hysterectomy experience from the patient's viewpoint. This perspective of inquiry will provide data as to women's perceptions of this experience, the adjustment strategies that they utilize as well as the social situations which impede or enhance their adjustment to changes. An understanding of these issues will broaden health professionals' knowledge of this experience and increase their effectiveness in meeting the needs of these women.

III. METHOD

Researchers generally agree that the nature of a research question, the purpose of a study, the current state of understanding about an area of interest, and the constraints of the informants or setting guide the investigator in choosing a method of inquiry (Field & Morse, 1985; Mishler, 1979). After a careful consideration of the above factors, this researcher selected a qualitative mode of inquiry to explore the experiences of women who undergo a hysterectomy. A qualitative approach was considered to be an appropriate and logical choice for several reasons. First, as little was known about the topic, the research question was categorized as exploratory (Diers, 1979). Second, the purpose of the study implied that a description of the experience of undergoing a hysterectomy be pursued from the hysterectomy patient's perspective. Finally, the choice of a qualitative approach was further justified by the fact that the experiences of women who undergo a hysterectomy have not been comprehensively and systematically examined, and that the existing knowledge in this area is fragmented and incomplete. In the following chapter, the qualitative method selected for this study will be presented. Furthermore, sample characteristics, issues of data collection and analysis, reliability and validity, as well as ethical considerations will also be discussed.

Grounded Theory

The specific qualitative research approach selected to conduct this study was the grounded theory method, developed by Glaser and Strauss in the late 1960's. A grounded theory approach is particularly useful for examining processes versus static phenomena (Field & Morse, 1985). This method considers the phenomenon under study in its totality (Chenitz & Swanson, 1986; Glaser & Strauss, 1967; Simms, 1981; Stern, 1980; Stern & Moxley, 1984) and enables the investigator to view the experience of undergoing a hysterectomy from the informant's perspective.

According to Hutchinson (1986), the generation of a grounded theory is based on

the following assumptions: (a) that individuals order and make sense of their environment although their world may appear disordered or nonsensical to observers, and (b) that certain groups of individuals share a specific social psychological problem that is not necessarily articulated. This fundamental problem is resolved by means of a basic social psychological process (Glaser, 1978). This study focused on a group of women who had undergone a hysterectomy. The utilization of a grounded theory approach provided a means to discover the dominant patterns of behavior relative to the specific context under study, and enabled the investigator to gain an understanding of what these women experienced as they adjusted to their bodily changes. A theory which describes how these women resolved and adjusted to their experience of undergoing a hysterectomy is the final outcome of this investigation.

Sample

In light of the purpose of this study, an attempt was made to maximize opportunities to obtain thick and rich descriptions of the experiences of women who undergo a hysterectomy. A nonprobability sampling method was utilized to select participants as the relevance of this sampling technique for qualitative research is well established (Morse, 1986). A purposeful nonprobability sample allowed the selection of women who were eager to be good informants and who were willing to share their experiences.

This investigation involved a total of 10 women who had undergone a hysterectomy within the previous month. The informants were selected from a large teaching hospital. Five gynecologists assisted the researcher to identify potential informants. During the initial contact with each woman, the investigator discussed the purpose of the research in general terms and explained that tape-recorded interviews, lasting approximately one hour each, would be required. Three potential informants were initially contacted by telephone a few days prior to their admission to hospital. These particular women refused to take part in the study as they were anxious about their upcoming surgery and felt that it would be unhelpful for them to participate in the investigation. Based on these responses, the

investigator decided to seek potential informants by approaching patients during the fourth or fifth day following their surgery. All of the potential informants who were initially approached after their hysterectomy agreed to participate in the study. On evaluation of this situation, it appeared that women felt more relaxed after the surgical event had occurred, and that a face-to-face encounter between the researcher and each participant facilitated the establishment of trusting relationships. Those women who expressed an interest to participate in the study were informed that appointments for interviews would be made with them after their discharge from the hospital.

Hysterectomy patients between the ages of 21 to 39 years of age who were English speaking, residents of the Edmonton area and who were able to interact in an interview situation met the inclusion criteria established for this study. The decision to study a group of young women who had undergone a hysterectomy was made following the suggestion by some investigators that women of childbearing age are particularly at risk of experiencing negative psychological consequences following a hysterectomy (Barker, 1968; Melody, 1962; Richards, 1973). Prior to the commencement of the first interview, a consent requesting permission to conduct the interviews and to tape-record the content of the interviews was obtained from each informant. In addition, biographical information was requested at this time and is presented in Table 1.

Data Collection

Since the researcher was seeking thick and rich descriptions of women's experiences, unstructured open-ended interviews were utilized to collect data. This data collection method is recognized as useful and appropriate when conducting exploratory research (Diers, 1979; Field & Morse, 1985). This particular method allowed the informant to guide the investigator into her world and facilitated the disclosure of issues that the woman considered important. In addition, this technique provided the researcher with maximum flexibility and allowed an opportunity to focus on a particular area or

Table 1: *Biographical Characteristics of the Informants*

	Characteristics				
Informants	Age	Marital Status	No. of children	Reason for Hysterectomy	Type of Hysterectomy *
1	28	M	4	Pain/Bleeding	Total
2	30	M	2	Pain/Bleeding	Total
3	39	M	0	Pain/Bleeding (Fibroid)	Total
4	34	M	2	Pain	Total & BSO
5	29	M	2	Pain/Bleeding	Total & LSO
6	38	M	5	Pain/Bleeding	Total
7	35	M	3	Pain	Total
8	29	M	2	Pain	Total & RSO
9	24	M	2	Pain/Bleeding	Total & LSO
10	32	D	2	Bleeding	Total & BSO

Note. Total = Removal of the uterus and cervix; BSO = Bilateral Salpingo-oophorectomy; RSO = Right Salpingo-oophorectomy; LSO = Left Salpingo-oophorectomy.

* All abdominal hysterectomies.

keep the focus broad.

Prior to the beginning of data collection, the investigator developed a plan to interview informants during three specific time periods of the hysterectomy experience: the first time prior to their admission to hospital, the second time at one month after the operation and again at three months in the recovery period. This plan was elaborated in order to enable the researcher to capture women's perceptions as they progressed through the experience of undergoing a hysterectomy. However, in light of the researcher's failure to locate women who were willing to participate in the study during the preoperative period, informants were interviewed at one and three months after their surgery. The interviews conducted with each informant lasted from 45 to 90 minutes. The number and length of interviews depended on the receptivity of the informants, their willingness to share information, and their contribution to the emerging theory. A total of 18 interviews were conducted in this investigation. All of the interviews were tape-recorded an subsequently transcribed. In addition, detailed fieldnotes further supplemented data collection.

As the majority of potential informants that were identified during visits to the host institution did not reside in the city of Edmonton, a decision was made to facilitate sampling and data collection. First, the inclusion criterion concerning the issue of residence was expanded to allow women who were residing in the surrounding areas of the city to be included in the study. Second, two methods of interviewing were chosen in order to adapt to this situation. The face-to-face interview method was used with three women who resided in the Edmonton area, while telephone interviews were conducted with seven informants who lived in the surrounding areas of the city.

The interviews conducted during the early stages of the study were directed by the informants' responses. As the data analysis progressed, the nature of the interviews changed. The investigator began to focus on particular areas and to ask more specific questions. The development of specific questions was prompted by the categories and

relationships that were emerging from the data. During the later stages of the study, the questions posed by the investigator were used to further substantiate the emerging categories and relationships and to extend the researcher's understanding of the data.

Data Analysis

The grounded theory approach promotes creative thinking as it requires that the researcher simultaneously collect, code, and analyze data (Hutchinson, 1986). In addition, unlike other research methods which follow a linear sequence of analysis, the grounded theory method is circular in nature (Glaser, 1978). This circularity involves that the researcher work within a matrix comprised of three basic activities: (a) coding the data, (b) classifying the codes into categorical schemes, and (c) discovering the core category. The emerging categories eventually become integrated into a substantive theory as the investigator moves back and forth between data collection and data analysis.

In this study, the analysis of the transcripts of interviews involved the elaboration of open, substantive codes from the issues and themes that the informants discussed during the interviews. Women's responses were coded by writing the names of the codes on the margins of the interview transcriptions. As data collection continued, these initial codes became condensed and were sorted into categories. Categories are defined as abstractions of the phenomena observed in the data (Glaser, 1978). The investigator developed categories which regrouped many of the initial codes. Additional data collection substantiated these emerging categories. Furthermore, the categories were compared to each other in order to ensure their mutual exclusivity. Throughout the analysis, the researcher also constantly compared every piece of data to every other piece of data to look for commonalities or negative cases across all of the interviews. A negative case was representative of the woman whose experience would negate the pattern of behavior emerging from the majority of interviews (Field & Morse, 1985).

As data collection continued, linkages between categories were established. These linkages were revised and modified, compared to existing theory, and validated by the

informants until all of the categories were integrated into a conceptual framework. Data collection ceased when categories were saturated and new data did not add to the current understanding.

Through a process of repeated analysis of the data, a core category called *Establishing Boundaries of Normality* evolved. Grounded in the data, *Establishing Boundaries of Normality* explained the major behaviors of hysterectomy patients. The core category is the process which holds all of the categories together and explains most of the variation in the data (Stern & Pyles, 1985).

The strategies of memoing and diagramming were utilized throughout the process of data analysis to enhance the researcher's ability to develop categories and identify linkages. Memo writing provided a useful means to keep track of ideas, questions, and hunches, and enabled the investigator to formulate hypotheses and to verify findings. In contrast, the use of diagrams increased the researcher's understanding of the data as these provided a visual representation of the emerging theory.

Reliability and Validity

Every qualitative researcher seeks to accurately conceptualize and describe the phenomenon being investigated (Field & Morse, 1985). Inherent to this endeavor is the researcher's responsibility to demonstrate the credibility of his or her findings since the credibility of findings partially determines the value of any type of scientific research, whether quantitative or qualitative (LeCompte & Goetz, 1982). In order to appropriately address the issue of credibility, the investigator must ensure that threats to the reliability and validity of the findings are minimized. Although all investigators attempt to establish the credibility of their findings, it must be recognized that the criteria for assessing the reliability and validity of qualitative studies are different from those utilized for quantitative studies because the methods and aims of qualitative research differ from those of quantitative research (Field & Morse, 1985; Sandelowski, 1986). In the following section, the strategies that the investigator used to enhance the reliability and validity of the findings

will be presented.

In this investigation, the first strategy utilized to ensure the establishment of reliable and valid findings was the selection of a suitable and useful sampling method. The criteria of appropriateness and adequacy have been suggested by Morse (1986) for evaluating sampling strategies in qualitative research. Morse defines the criterion of appropriateness as referring "to the degree in which the method of sampling 'fits' the purpose of the study as determined by the research question" (p. 185). The central objective of the data collection for this study was to obtain data that were comprehensive, relevant, and detailed. Consequently, a nonprobability sampling method was utilized since it facilitates the development of an understanding of the phenomenon being investigated, and it enhances the investigator's ability to obtain thick descriptions and to elicit meaning (Morse, 1986). The assumption underlying a nonprobability sampling method is "that all actors in a setting are not equally informed about the knowledge sought by the investigator" (Morse, 1986, p. 183). The particular kind of nonprobability sampling that was utilized in this study was a purposeful or theoretical form of sampling as this approach allows the selection of participants who will meet the theoretical needs of the investigation (Field & Morse, 1985). The use of this sampling method effectively guided the development of the emerging theory since it enabled the researcher to seek the full range of variation in each emerging category.

In contrast to the criterion of appropriateness, the adequacy of a sampling approach refers to the quality, completeness, and amount of information provided by the informants (Morse, 1986). In this study, the researcher ensured that the criterion of adequacy was met by continuing theoretical sampling until all categories were saturated. In other words, sampling and data collection ceased when no new information was found, information was repetitive, and the researcher achieved a sense of coherence (Morse, 1986). In addition, the internal validity of findings was further strengthened by utilizing theoretical sampling of the literature and by actively seeking negative cases.

Additional strategies were incorporated into this study to minimize threats to

reliability and validity. First, the researcher attempted to verify the data by asking informants about the same content. This type of concurrent validation enhanced the accuracy of the data collection. Second, the investigator's interpretation of the data was confirmed and validated by the informants in order to minimize bias or distortion. Third, the researcher's interpretation of the data was also reviewed with professional colleagues who served as secondary informants. Fourth, examples were used to explain and present the data. Finally, the investigator sought to recognize and explore her assumptions regarding the experience of a hysterectomy in order to develop an understanding of the effect that she was imposing on the data collection and analysis. Repeated discussions with other individuals was a valuable means for the researcher to explore the biases and assumptions she held. For example, the assumption that the recovery from surgery would be more stressful than the preoperative phase of the illness was recognized through discussions with other individuals. In turn, the recognition of this assumption enabled the researcher to examine its foundation with the informants.

Ethical Considerations

Several strategies were used to establish the ethical adequacy of this investigation. First, ethical clearance was obtained from the ethical review committee of the Faculty of Nursing, University of Alberta and the host institution. Second, an informed consent was obtained from each of the informants prior to the beginning of the first interview. A written informed consent was obtained from those participants who were interviewed by means of the face-to-face interview method (see Appendix). A verbal, tape-recorded informed consent was obtained from those informants who were interviewed by telephone. In this instance, the written consent form was read to the informant over the telephone. All of the participants were informed about the nature of the study. In addition, they were all informed that participation in the investigation was voluntary and that they could withdraw from the study at any time. Third, the anonymity of the informants was maintained by altering or deleting all identifying information within the texts of the transcriptions and by

assigning a code number to each participant. The names, addresses, and phone numbers of the informants as well as the tape-recorded interviews were kept in a locked file throughout the course of the study. The tape-recorded interviews, the interview transcriptions, and the names and addresses of the participants were destroyed at the conclusion of the project. Finally, it was anticipated that the process of expressing one's experience of undergoing a hysterectomy would be beneficial to the informant. To decrease the likelihood of harm or emotional trauma for the informant, information regarding professional services was available to the informants at the discretion of the investigator.

IV. FINDINGS

The experience of women who undergo a hysterectomy is comprised of three interdependent stages: the disruption of the body, the struggle to preserve wholeness, and the recovery (Figure 1). In the first stage, the woman attempts to understand and cope with her health problem, and as she fails in her efforts to manage the symptoms, she is faced with the possibility of having a hysterectomy. Eventually, the decision to undergo this surgery is made. During the second stage, the woman engages in a struggle to minimize her sense of fragmentation and loss of control. In the third stage, the woman begins to adjust to the bodily changes resulting from the hysterectomy and attempts to come to terms with her surgery. Throughout the course of the illness and surgery, the woman constantly evaluated her symptoms and experiences by determining what was normal and what was abnormal by comparing present symptoms with her past experiences and those of her friends, thus establishing a composite frame of reference of the "boundaries of normality".

In the following pages, the experience of women who undergo a hysterectomy will be presented. The strategies that these women used to address and resolve their health problem will be examined. Finally, the ways in which they maintained their sense of integrity about their bodies and their lives will be explored.

Establishing the Boundaries of Normality

The experience of women who undergo a hysterectomy begins with the onset of symptoms. In the subsequent period, women implemented a number of strategies, attempting to control, limit and normalize symptoms. In this investigation, *establishing the boundaries of normality* emerged as the basic psychological process by which women coped with their symptoms and with the experience of a hysterectomy.

Establishing the boundaries of normality is defined as a process which involves incorporating what is unknown into that which is known, ordinary, and familiar. Women sought to establish boundaries of normality by developing a frame of reference which gave

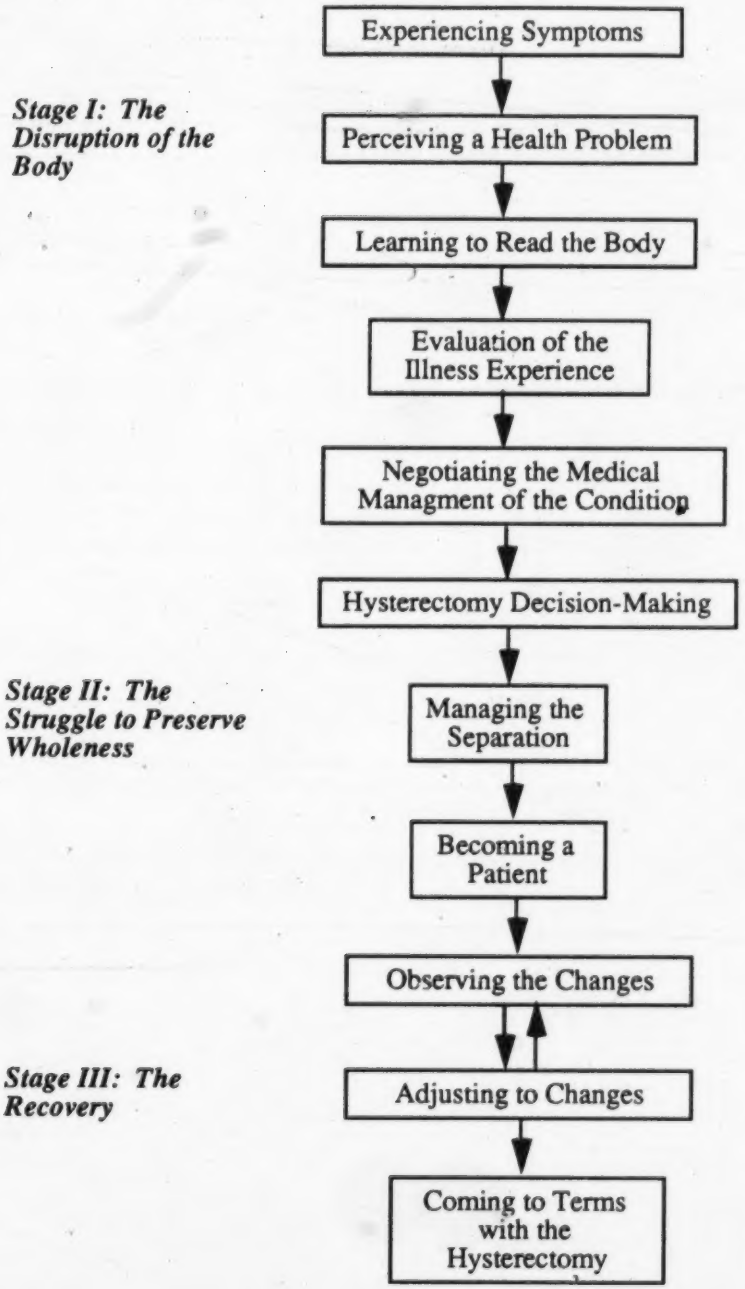
Stage I: The Disruption of the Body
Experiencing Symptoms
Perceiving a Health Problem
Learning to Read the Body
Evaluation of the Illness Experience
Negotiating the Medical Managment of the Condition
Hysterectomy Decision-Making
Stage II: The Struggle to Preserve Wholeness
Managing the Separation
Becoming a Patient
Observing the Changes
Stage III: The Recovery
Adjusting to Changes
Coming to Terms with the Hysterectomy

Figure 1. The Experience of Women who Undergo a Hysterectomy

coherence to their experience of bodily changes. Through this process, the informants attempted to understand their health problem, to remain in control of bodily changes and to protect their self-esteem (See Figure 2.).

As these women experienced symptoms, they reviewed their past menstrual experiences and compared their present symptoms with their friends' beliefs and opinions to construct a "normative" frame of reference. For example, these women would compare the amount of menstrual flow, the severity of cramping or the degree of back pain with the severity of symptoms experienced in the past and the experiences of their friends to determine if their own symptoms were yet "serious" or still within the normal range. Comparing their symptoms, within a frame of reference, enabled women to comprehend that they did have a health problem, and guided them in selecting and implementing coping measures. The frame of reference also provided a baseline for identifying new symptoms as they appeared.

In addition, the women used this frame of reference to address and deny the false beliefs of others related to their health problem and the impending hysterectomy. This enabled these women to maintain their lives as normally as possible, and to protect themselves from being devalued as individuals. As one informant stated:

> I think the one thing that everybody worries about is because so many times when you hear people say the woman's had a hysterectomy they associate that her personality, her mind is also going to be affected. "Oh, they've pulled everything out you know. She's going to be crying a lot, she won't understand." That seems to worry everybody because you're not just losing that womanly part of your body, you're afraid you're going to lose part of your marbles, part of your brain, and people are going to insinuate you can't reason well anymore because you had a hysterectomy, and I think that is why we are so concerned about being normal. I think I was but before I had this operation .... I didn't come about this operation just like that overnight, you know. I knew about it some time ago, so I had time to learn a lot and do some reading on it and know that most of the time that has nothing to do with your head, but a lot of people can't see that .... I think that's what worries us. Am I normal again now? Can I reason things out ? Am I not going to burst out crying for anything?

However, their "boundaries of normality" were repeatedly revised as the health

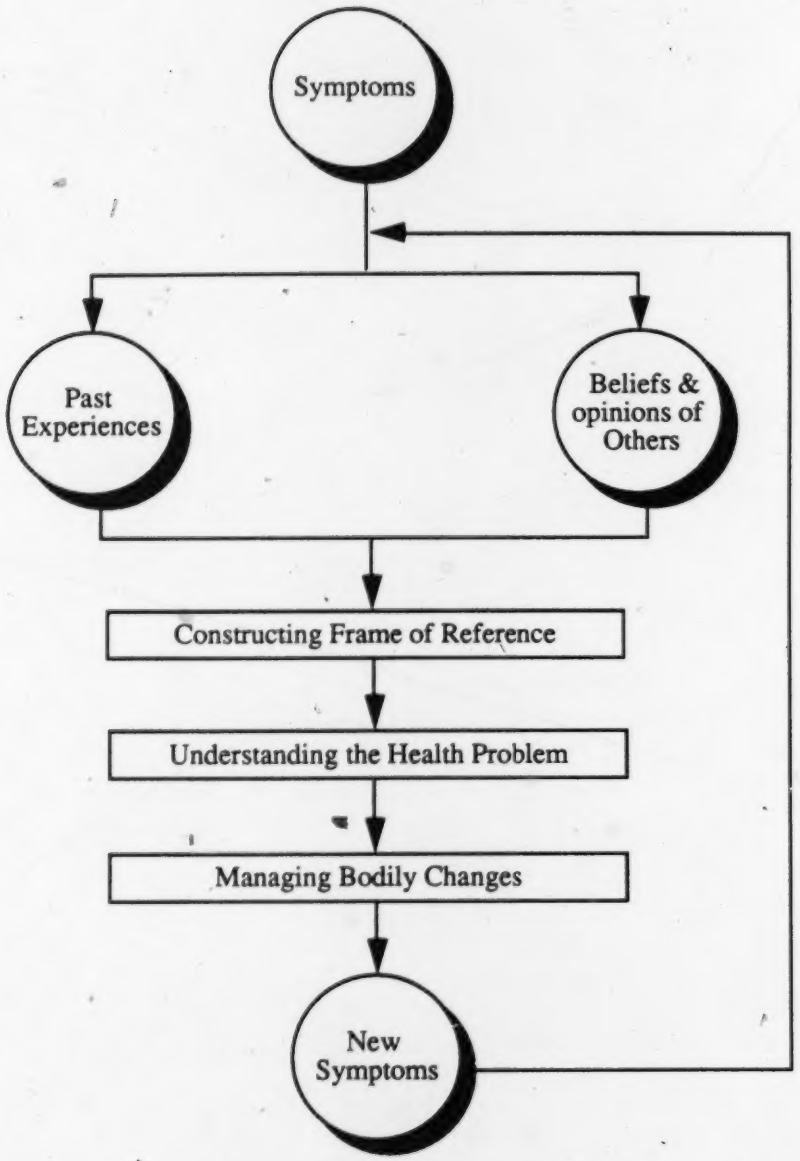

Figure 2. Establishing the Boundaries of Normality

problem progressed and as new events and bodily changes occurred. The increasing severity of symptoms prompted the women to continuously test and alter their frame of reference by discussing aspects of their problem with significant others and physicians. This testing assisted them in maintaining their sense of competence about their changing situation. The successful maintenance of the notion that their symptoms were still normal was contingent upon the willingness of others to assist women in revising their frame of reference and to provide emotional and practical support.

Stage I: The Disruption of the Body

Experiencing the Symptoms

Each woman who engaged in the process of preparing for, going through, and recovering from a hysterectomy did so in her own unique way. However, after reviewing interviews conducted with the ten women in this study, it became apparent that although some variation existed in terms of their experiences with symptoms, there were also very definite patterns of behavior common to all members of the group.

In the interviews, the researcher requested that each informant describe exactly what happened from the time that "problems with the uterus" began. From this question, details and descriptions related to various symptoms and their characteristics emerged. The women's experiences with symptoms represents the first phase of the *Stage of Disruption* . Various combinations of eight major symptoms were outlined by informants: pain, bleeding, weakness, fatigue, shortness of breath, swelling, headaches, and lack of emotional control. Furthermore, informants identified the symptoms of pain and bleeding as being central to their health problem. Time of occurrence, duration, frequency, and intensity were the symptom characteristics most often discussed. Figure 3 illustrates a variety of descriptors that the women ascribed to the symptoms of pain and bleeding.

The issue of how symptoms affected life-style was extensively described by all informants. Areas in which disturbances were most acutely experienced involved sexuality and, for those who had not had a tubal ligation, fertility control. In addition, acute

Symptom Type	Time of Occurrence	Duration of Episode	Frequency	Intensity
•Pain	•Before/following ovulation •Before/during menstruation •Throughout cycle •During/following intercourse •During/following activities of daily living, i.e., lifting, pushing, exercising •Following specific events, i.e., vaginal exam, pap smear, laparoscopy, tubal ligation	•From a few minutes to 2-3 days	•From one to several times a day •Every day	•Very light •Aching •Sore •Sharp •Heavy and strong •Severe •Like labour
•Bleeding	•During/following ovulation •During menstruation •Throughout cycle •During/following intercourse •During/following activities of daily living, i.e., lifting, pushing, exercising •Following specific events, i.e., vaginal exam, tubal ligation	•From a few hours to several days	•From one to several times a day •Every day	•Spotting •Light •Moderate •Heavy •Saturating •With or without small to large clots

Figure 3. Descriptors of Pain and Bleeding

disturbances were identified in the areas of role performance in the workplace as well as in the ability to function in the home.

Three of the five women in the sample, who had not had tubal ligations, expressed a great deal of anxiety and concern regarding the control of their fertility. Conventional methods of contraception, such as the birth control pill, were perceived as unreliable since the body's natural rhythm was disrupted by the symptom episodes. One woman said:

> I. I'd stay up until I made sure he was asleep or something, then I 'd go to bed, or I'd sleep on the couch, not very often but, actually, quite a few times. You just get these silly ideas in your head. Don't touch me, I'll get pregnant. That's the way I was sometimes. I'd go like 42 days without a period and, oh God! Am I pregnant now? Then, it [the bleeding] would come, bang, bang, bang.
>
> R. It was hard to know what was going on?
>
> I. Well, I couldn't. I'd have to keep charts if I wanted to get pregnant and when I wanted to get pregnant.

The presence of symptoms affected and disturbed these women's sexuality. They experienced a decrease in their desire for intercourse since this exacerbated the symptoms. They were also concerned about feeling unattractive, their partners possible loss of interest in the relationship, and the possibility of conceiving an unwanted or, in some cases, an unaffordable child. One woman explained how she discussed this situation with her physician:

> I said, for the last four years, our sex life is the pits because it's getting to a point like for awhile there, well actually until now, for about three years straight I guess, sex wasn't interesting to me at all. I think it was probably because of my pains and what I was going through. I don't know, but I feel very sorry for my husband because he's been a very patient man. Most men wouldn't put up with something like that. They're usually used to having sex two or three times a week, and when it was getting to be like once or twice a month, you know, it's not fair to him either. And that was bothering me in the back of my mind. I told my physician, other than that we get along fine. I said my husband's been very patient. There are days when he has to have it, and, you know, we make do somehow. Unfortunately, then I suffer for about three or four days, and I was telling him about that. And he said, "Well, what do you want to do?"

For women who were employed outside the home, coping with symptoms and maintaining energy often meant using sick days as one of the measures to establish symptom control. This was especially true for informants who held jobs that required a great deal of physical activity, such as, lifting, pushing, and pulling heavy objects. Those who attended work in spite of the severity of symptoms found that their effectiveness and the quality of their performance suffered. They lacked stamina and felt exhausted most of the time. In addition, adhering to strict schedules made it difficult for these informants to control the situation as well as maintain their energy level at work and with their families:

> I started working a year and a half ago. That was one of the reasons this came to a head, too. When I was at home, I could cope because you can lay on the couch all day or whatever . . . . If things don't get done it's not so bad, but at work, you know, you can't be expected to take it off all the time.

Those informants who worked on their own time and at their own pace had greater flexibility in terms of implementing coping strategies. As a result, they were more successful in maintaining their energy and controlling symptoms than the women whose employment did not allow for such flexibility.

The effects of symptoms were experienced in a variety of ways in the home setting. Women had difficulty fulfilling their role as mothers when symptom episodes were severe. Relinquishing household tasks to the spouse or to an older child was very difficult for the women in this study. The women were frustrated when they did not have the strength or stamina to perform their usual activities. They became upset when implementing coping measures, which often involved sleeping after taking analgesics or resulted in postponed plans for family outings, as well as, time away from children and spouses:

> It really got to me because I wouldn't know where, I could be on a field trip with the kids, you know. I knew if I was driving somewhere and it happened, I couldn't drive, I would have to stop the vehicle.

Increased irritability and decreased tolerance of family demands were perceived by

some as effects of pain and/or bleeding. For others, lack of emotional control was identified as a symptom separate and apart from the pain and/or bleeding. The following statement illustrates the first type of perception related to lack of emotional control:

R. You were bleeding quite a bit. Were you feeling weak?

I. Yeah, you just get to a point where you're so tired, so tired all the time, you know. "Get these kids out of here!" You know, they just get on your nerves so much, and it was steady.

The second type of perception is illustrated by the following:

I. I had mood swings so bad that one minute I'd be happy and the next minute I'd be tearing him apart or anybody else that stepped in my way.

R. They would get chewed up pretty good?

I. Yeah, and then I'd sit there and go "Holy but Jesus," you know, and then I'd go back to mellow again and just hateful, hateful moods. "Just get out of my sight." "Don't talk to me, don't come near me." "I'll kill anybody that comes near me." I thought, "Oh I can't handle this anymore."—one minute I'm in a good mood, and then, for absolutely no reason, I'd turn into a complete animal. I'm surprised anybody still talks to me. I've snapped off more than a few heads.

Finally, the above two variations in perception were also observed when women discussed weakness, fatigue, shortness of breath, swelling, and headaches. For example, some associated weakness, fatigue, and shortness of breath with their loss of blood. Others, in this study, did not make this association and perceived these symptoms as separate entities.

Perceiving a Health Problem

Some of the women in this study lived with relatively severe symptoms for as long as ten years before becoming concerned enough to seek medical help, and to seriously consider the final step of having a hysterectomy. The informants realized they had a health problem when certain conditions in their lives changed. However, this health problem was ignored as long as the following four conditions remained unchanged with the symptoms: (a) they were few in number; (b) they were consistent and predictable; (c) they were not

perceived to alter life-style in unacceptable ways; and (d) they could be justified as normal occurrences of the female life-cycle when other women advised them that the symptoms were a "part of being a woman":

> I was a late bloomer as they classify it because I didn't start my period till I was fifteen years old, and from day one, I had severe cramps, a lot of very bad cramps, since I was a little girl, you know, fifteen. I was usually sick the first two days, right in bed with the cramps, and my mom always brought me up to believe that that was just part of life. And I went for so many years, and then when I had my first child everybody said, "Oh have a baby, and it will get easier." And with me, it went the exact opposite, it got worse.

The women in this study became concerned and anxious when symptom characteristics changed, when new symptoms appeared, when significant others began to view symptoms as serious, when measures used to achieve symptom control demanded more time and energy, or when measures failed to produce the desired level of control. These occurrences resulted in the women's realization that their symptoms indicated a problem with the uterus. The perception of having a health problem represents the second phase of the *Stage of Disruption* . The realization that they were ill was the main factor that forced the informants to systematically explore the symptoms in order to identify their boundaries of normality. Establishing these boundaries included assessing the characteristics, context, and evolution of symptoms, as well as, assessing and testing a variety of means or options women used to obtain relief.

Learning to Read the Body

Women learned to "read their bodies" when they became concerned and anxious about their symptoms, and recognized that they were ill. This *Learning to Read the Body* is the third phase of the *Stage of Disruption* , and it is defined as a set of specific activities systematically implemented by women for the purpose of making sense of, coping with, and coming to terms with their health problem. Activities implemented by informants in this phase included: evaluating symptoms and their characteristics; identifying and recognizing triggers of symptoms; assessing and testing options to find relief and to find

the cause of the health problem; and seeking information and comparing symptoms with other women. These activities were instrumental in prolonging this particular phase since the consideration, testing, and evaluation of options often involved a "wait and see" period. In addition, these activities tended to be repeated over and over again by the women in this study, and the cyclical nature of these activities represents a second factor which prolonged this phase.

When the women initially began the phase of *Learning to Read the Body*, they altered certain aspects of their lives on their own to establish control over their symptoms and to assess whether these changes would shed light on the possible causes of the health problem. The women's concerns about their bodies increased as their health problem intensified and as coping measures began to fail to relieve their symptoms. To increase their success in managing their health problem, the women in this study gradually involved significant others to help them manage symptoms and make sense of the situation. This involvement of others often generated new options for finding relief as well as new ideas about the possible causes of their symptoms.

In addition to involving more and more individuals, the options considered and tested during this phase also became more complex. The women in this study decided which options to use by considering the degree of alteration they would experience within their bodies as well as the effects these options would have on their family and work environments. Consuming a variety of over-the-counter analgesics represents one kind of option which produced alterations within these women's bodies as well as in their environment. Pain could be controlled or relieved by the ingestion of analgesics; however, drowsiness often resulted from this coping measure.

Over time, and after having considered, tested, and evaluated a variety of options which yielded little relief and few answers, the women in this study became "fed up" with having to plan their lives around their symptoms. They also became increasingly concerned and anxious about their limited success in managing symptoms. In addition,

significant others, such as the spouse, were also affected by the difficulties that these women were experiencing. For example, some spouses expressed their worry and fear that the illness was becoming quite serious, and they urged their wives to consult a physician. Other husbands reacted differently, over time, they became less tolerant of the effects of their wives' symptoms. The significant others' reactions about the health problem and the women's increasing inability to manage their symptoms were the two factors which motivated informants to seek assistance from health professionals.

When the women in this study consulted physicians, they sought confirmation and labeling of their illness as well as medical management of their health problem. As a result of consulting physicians, these women were faced with a variety of medical options. Since these options often involved procedures that had to be carried out in such inconvenient settings as the hospital, they were viewed as disruptive. These options also caused a greater degree of alteration to their bodies and environment than the previously tested coping measures suggested by significant others. Agreeing and submitting to day surgery for a laparoscopy illustrates this particular situation.

Individual differences influenced the length of time spent and the energy expended in attempting to read the body and discover the sense of the symptoms. These individual differences included: the woman's knowledge base about her body and her beliefs about that knowledge base, her problem solving and information seeking behaviors, her tolerance to anxiety, pain, and bleeding, as well as, her values and beliefs related to her symptoms and her uterus. In addition, contextual differences were also found to be influencing factors in this particular phase. These differences refer to family, work, and relationship demands, the nature and quality of the woman's support system, the values and beliefs of significant others about symptoms as well as their reactions to them and to the means used to achieve symptom control:

R. How did your husband feel about that?

I. He was the same way, he was tired because I got very severe PMS

> [Premenstrual Syndrome] where I would literally throw things. I got almost an insane feeling about a week before my period, and I would break glasses, I would throw things. I was, I mean the worse person. I could say other names for myself, but he couldn't really deal with that anymore, and it was, I was like a time bomb ready to go off at any time when I had that.

Related to the phase of *Learning to Read the Body*, a definite structure emerged from the interview data. As shown in Figure 4, specific patterns of behavior, common to all women in this study, will be explained and illustrated in the remaining parts of this section.

Exploring/Recognizing Triggers

When engaging in the phase of *Learning to Read the Body*, informants first attempted to explore, by themselves and later with others, a variety of possibilities or factors which might trigger the onset of symptoms. Exploring and recognizing triggers helped women to set limits to this particular phase. These limits centered on the types of triggers that were explored. Although the factors considered were many and varied, they were found to fit under the following three general areas: (a) the menstrual cycle, (b) activities of daily living, and (c) events occurring in their lives.

Cycle Triggers

When exploring cycle triggers, the women in this study examined symptoms in terms of their menstrual cycle to determine whether there was a relationship between symptom characteristics and specific stages of the cycle. Assessment of this trigger was carried out over a period of several cycles to establish the validity of relationships. In addition, exploring cycle triggers was found to be the starting point for all the informants in this phase since it was an aspect of their lives that they were familiar with and had assessed before:

> That's why I was so surprised cause like the cramps over the years, the cramps had been really bad. I've tried all kinds of different drugs and stuff to get them under control, but over the last few years, it's really been bad. They always started about a week before. I couldn't do nothing the first few days into the period, but other than that, there was nothing out of the ordinary, nothing to pay any attention to.

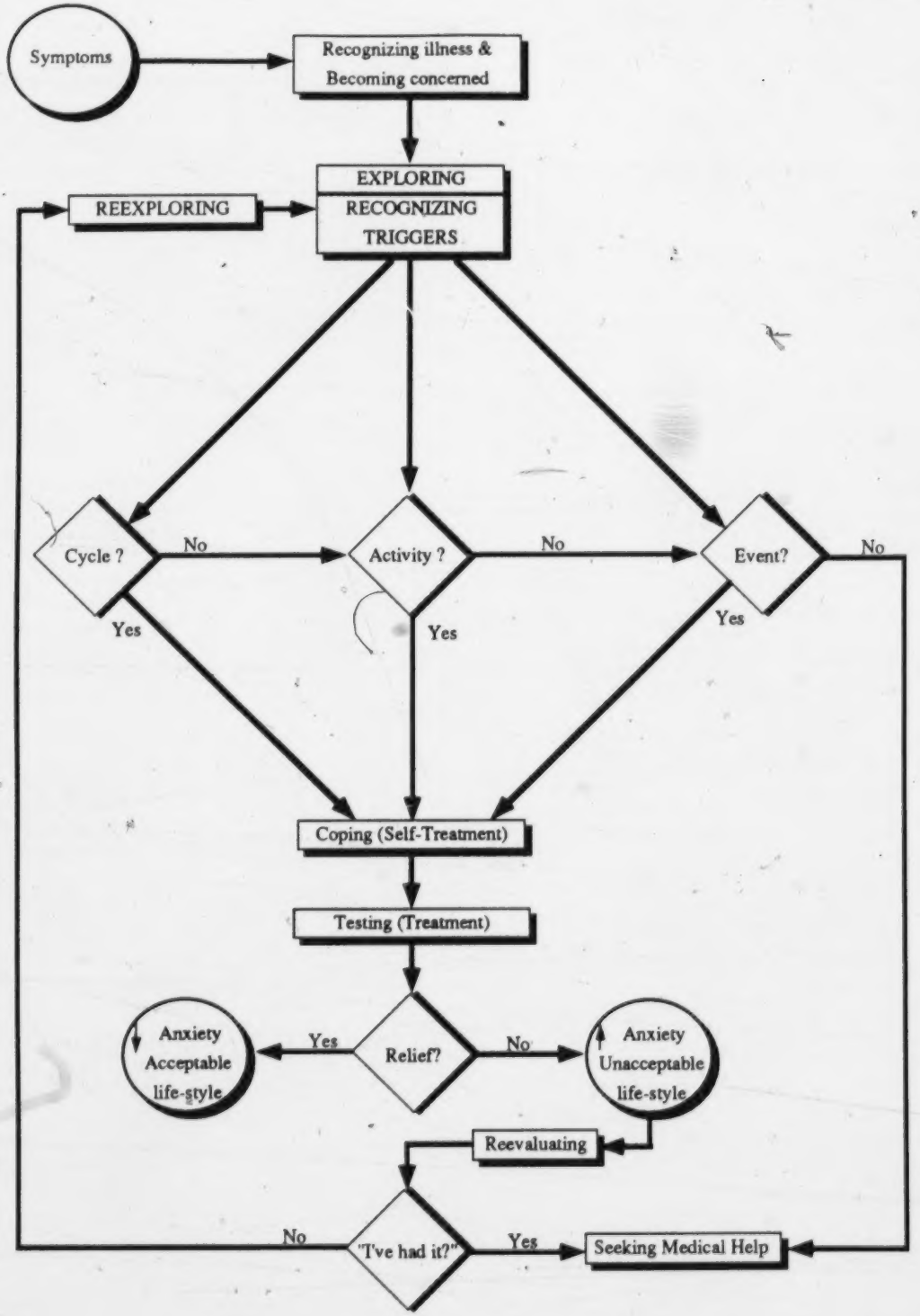

Figure 4. Learning to Read the Body

Except when symptoms were extremely severe, the examination of cycle triggers was carried out with little or no interaction with significant others. This initial questioning was focused specifically on the body's natural rhythm, and as such; generally did not lead women to discuss their problem with others.

When the women found a cycle trigger that was directly related to their symptoms, they attempted to control the situation by testing a variety of self-treatment strategies. Examples of strategies that informants tested over time include: consuming a variety of over-the-counter or prescription drugs, increasing rest periods, and decreasing activities, such as, intercourse and family outings, at specific times during the cycle.

When these strategies brought relief, the women's anxiety about their bodies decreased, and they incorporated these measures into their life-style. On the other hand, when strategies failed to relieve symptoms, the women's anxiety increased. They would then seek to discover and test new options:

> I started out using Mydol® and Aspirin® and over-the-counter pain killers, but they didn't seem to help. Usually I would go to bed with the electric blanket and turn it up full blast and drink tea. For some reason, tea seemed to help, and this would be for a day, usually the first day. And then, when I went on the pill, all of that stopped, and I had a very mild period.

Over time, strategies used to alleviate symptoms failed to control the health problem, and the informants had to reevaluate the symptoms, comparing them with past experiences. They also began to discuss their symptoms with their spouses and compared aspects of their problem with other women. These activities often led to new options, new ideas about the causes of their symptoms, and the discovery of new triggers. Finally, talking about their concerns with others provided informants with some support and reassurance.

Activity Triggers

The activity trigger was considered when self-treatment strategies were no longer effective and when recognized cycle triggers no longer explained the onset of symptoms.

In this case, symptom characteristics were examined for any relationship with daily activities, such as, exercises, vacuuming, lifting, pushing, pulling or during intercourse:

> For at least ten years I had pain on the right side, and that pain would vary depending on a lot of things, like my weight, how often sexual intercourse was being performed, and then also it would have to do with my periods, and when I was really physically active.

When a relationship was recognized between symptom characteristics and specific activities, the women tested new options, such as, decreasing the frequency of problem activities or relinquishing them to others. If relief was obtained, anxiety decreased, and these additional measures were integrated into the informants' life-style. If there was no relief, informants reevaluated their health problem with significant others and compared their symptoms with other women. Again, new options, new ideas about cause, and new triggers to be considered often emerged from these exchanges.

Event Triggers

The event trigger, the final type of trigger, was examined when identified cycle and activity triggers no longer explained the onset of symptoms. In this case, women explored their symptoms by looking for a relationship between the symptoms and specific events in their lives. Informants believed events such as giving birth, vaginal infections, a miscarriage, or a tubal ligation, or stresses, such as looking for work, and financial difficulties, to be related to the symptoms:

> After I had my son, when I had my first period after, for no apparent reason, I'd get this sharp, stabbing pain right up inside of me. I was sitting here and then all of a sudden, this stabbing pain would come up.

The women in this study attempted to cope on their own when a relationship between symptoms and a particular life event was identified. In this case, they watched the symptoms to assess whether the health problem decreased over time. Informants gradually experienced a great deal of anxiety and concern about their bodies when symptoms did not subside and when new symptoms appeared. Eventually, the women realized they were no

longer capable of managing their health problem by themselves, and they sought medical help to resolve their health problem.

Trigger Combinations

As their health problem became more complex and difficult to manage, the women in this study consulted physicians and continued their attempts to read their bodies with significants others. Over time, most of the informants identified a number of triggers related to their symptoms. A variety of trigger combinations were recognized, and a number of self-treatment strategies, which were more or less effective, were developed to deal with the health problem. This situation was gradually translated into an unacceptable life-style where the health problem ruled the informants' liv

> This started going on and on. The periods lasted longer, cramps were getting a lot worse; they started almost a week and a half before the period, going through all that. I went back to the doctor, see what I could get for it. I think he took another test, and everything was clear. One day, I started getting hostile with him. I was really getting frustrated. I started getting a lot of pain just by doing a little bit of pushing, and the next thing, if I lifted anything heavy, I'd get it. And always with the pain, I got bleeding, spotting, and the clots were really getting huge, and then, my period would stop, and then you figured you were all finished, and three or four days later, fluuushhh, one big clot, no warning, no nothing.

Within the course of learning to read the body, only one informant did not engage, to any great extent, in testing self-treatment strategies. In this instance, this woman failed to identify triggers of symptoms in her life. Furthermore, she was not only concerned and anxious about her illness, but she was very fearful of cancer since she had been treated a number of years earlier for cancer of the cervix. Unlike the other nine informants, this woman immediately sought medical assistance to manage her health problem. This particular pattern of behavior is represented in Figure 4 by the lateral pathway between each type of trigger:

> It was nothing that was definite. You couldn't put a finger on when you were going to get it. Like it had nothing to do with the menstrual cycle at all, nothing. Like I don't know how to explain it. I could be sitting or standing or something and just get these sharp pains.

Evaluation of the Illness Experience

The outcome of the informants' interactions with others directly affected how they viewed and coped with their illness during the *Learning to Read the Body* phase. Husbands, significant women such as, mothers or close female friends, and physicians were the types of people that these women approached to help them address the issues surrounding their health problem.

The informants sought to measure the impact of their health problem on their relationship with their husbands and on the family as a whole when they talked about their symptoms with their spouses. They also attempted to obtain their support and assistance with tasks in the home. The openness of spouses to recognize, support, and discuss the health problem varied greatly in the sample. Several of the women said their spouses recognized and were willing to discuss their health problem. Some of these husbands actively supported their wives with tasks in the home, while others provided limited assistance in this area.

One of the women in this study was divorced and became involved in another relationship during the *Stage of Disruption*. The involvement of this significant other in the process was less intense than the involvement of the other informants' husbands. In this instance, the woman identified her mother as the individual who assisted and supported her the most during her illness.

Some of the women in this study said their spouses had difficulty recognizing the existence of their illness and were not open to discussing the issues surrounding their health problem. These women added that they received no emotional and functional support from their husbands; consequently, they experienced great difficulties in accurately measuring the impact of their health problem on their marriage:

I. Yeah, it was very trying on the relationship I'll tell you. We've been married ten years now, and the last three, it's suppose to be the first three or five or whatever . . .

R. That are the hardest?

I. That's right.

R. So for you it's been the last three?

I. Yeah, because you don't, I don't know how to say this—um . . . you don't know if he's lost interest or something like that or something to that effect.

When the informants approached the significant women in their lives, they were able to freely discuss most issues surrounding their health problem. These individuals quickly recognized the illness, and they displayed greater empathy than spouses since many of them had experienced this type of a health problem and, therefore, had a good understanding of its impact on the informant as well as on her marital and familial relationships. In many instances, significant women were valuable sources of information and support since they could explain the symptoms, provide reassurance, and suggest new options for finding relief:

I. I tried these different kinds of herbs and things. My aunt sent away somewhere and got me those. I was on those for a month or more.

R. Where did you get that information, about the herbs, about things like that?

I. Well, it was my aunt who told me that these were mixed with vitamins and stuff, and they were suppose to be high, really high in vitamins and everything, and she was on them and she thought well, might as well try them.

Some of the informants experienced problems in finding significant women from whom to obtain support and assistance. For example, one woman in this study had little contact with the significant women in her life. In this instance, her mother and sisters did not live in this country, and she had few close female friends residing in the city. She said this situation made it difficult for her to cope and understand her health problem:

> I felt lonely, alone, not knowing what's happening and what's not happening, you know.

The recognition of the health problem by the spouse and the accessibility of

significant women emerged as two important factors influencing the way women in this study viewed and coped with their illness during the *Learning to Read the Body* phase. The outcomes resulting from the presence or the absence of one or both of these factors are described and examined below and illustrated in the typology in Figure 5.

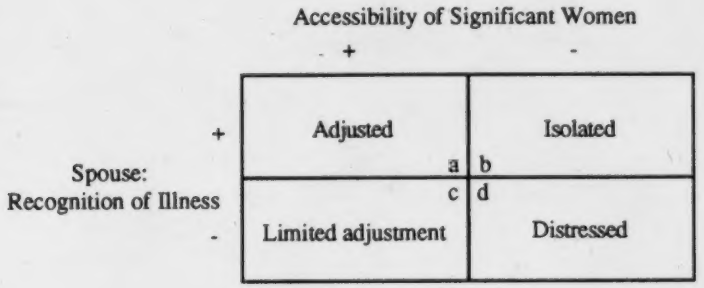

Figure 5. Influence of Significant Others on Women's Coping and View of Illness.

The women in this study were able to adjust to their illness when spouses recognized their health problem and when there were significant women to provide emotional support and information (Cell a). In this instance, informants reported that they were supported and assisted by their husbands, which made it possible for them to manage their illness by implementing a variety of coping measures to relieve their symptoms. The information provided by significant women helped these informants to develop an "explanatory model" of their illness. The notion of explanatory models refers to the ways in which a woman's private experience of symptoms was articulated and discussed. These explanatory models rendered the illness experience intelligible to others and to the informants, and allowed them to expand their repertoire of coping strategies as they progressed in the *Stage of Disruption*. As a result, these particular women managed their illness for a long period of time before seeking medical assistance.

The informants felt isolated when they could not find significant women to provide

support and information (Cell b). Although their spouses recognized the existence of their health problem, these particular women had no other references to compare symptoms and so they felt limited in their ability to cope. They had difficulty developing an explanatory model of their illness, and they could not expand their repertoire of coping strategies during the *Learning to Read the Body* phase since opportunities for communicating their concerns to significant women were few or nonexistent. Consequently, they tended to seek medical assistance to manage and understand their condition very early in their illness.

Informants felt limited in their ability to adjust to their illness when spouses did not recognize their health problem (Cell c). In this instance, the informants had access to information from significant women which helped them to develop an explanatory model of their health problem. Women significant to the informants also suggested a variety of coping measures for relieving symptoms. However, these informants often could not implement particular coping strategies, such as, reducing the frequency of intercourse or relinquishing tasks to others, since spouses viewed these measures as disruptive and unwarranted. These particular women said they attempted to cope as best they could, but they eventually sought medical assistance as the health problem became more acute and the strain in their marital relationship increased.

The women in this study felt distressed about their illness when spouses did not recognize their health problem and when significant women were inaccessible (Cell d). In these cases, informants were very concerned about their health problem and became afraid as they failed to make sense of it. They were limited in their attempts to cope during the *Learning to Read the Body* phase since spouses were intolerant of coping measures and their repertoire of strategies to manage symptoms was poor. Like women who had little access to significant women (Cell b), these informants also tended to seek medical assistance early in their illness.

As they progressed in the *Stage of Disruption*, certain events were identified to improve or impede the women's ability to cope, and these events changed their perception

of their illness. The events that were involved in these changes include: (a) the provision of medical information which confirmed the illness to the spouse and resulted in his recognition of the problem; (b) the gradual loss of emotional and functional support from spouses as they became tired of dealing with their wives' illness; (c) an increased accessibility to significant women; and (d) a decreased accessibility to significant women.

Consultation with physicians was a coping strategy implemented during the *Learning to Read the Body* phase. The women selected and tested this particular measure in light of their increasing inability to appropriately manage symptoms and in response to a variety of positive or negative cues from spouses and significant women. For example, spouses who expressed their concerns about the illness and urged their wives to see a doctor illustrate a positive cue. In contrast, not recognizing or being unconvinced of the existence of the health problem represents a negative cue. In this instance, women viewed consulting a doctor as the next logical step to convince their spouses that they were ill.

When the informants consulted physicians, they sought confirmation and labeling of their illness as well as medical management of their health problem. They wanted to identify the cause of their problem and obtain expert advice on how to manage and resolve the symptoms. The women's success in addressing these issues with their physicians varied greatly in this study. A few informants were successful in their initial interactions with their doctors. In these instances, they said their physicians acknowledged their illness and demonstrated empathy and respect during encounters:

> Yeah, he let me read the report from the laparoscopy, which, like I said, I don't know of any other doctor that would let you read the report and then sit down and explain it to you.

> I went to a doctor that really straightened everything out. He was a very patient, very good doctor. He would really listen, and his diagnosis was very good on a great many things, and he actually educated us more than any doctor we've ever known. He's the one who explained that things were not really critical, but that it would not really get better. And he explained to me, then, when things did get kind of bad just before that last child was born that he thought it was better for me to have a hysterectomy done. We told him no, and he understood, and he said that he would try and help us, you know, as

> long as my health was still doing alright, he would help us as much as possible.

The majority of the women, however, had little or no success in their initial encounters. In these instances, the interactions with physicians did not address the concerns of these women. These consultations frustrated the informants since their doctors did not acknowledge the impact of the illness on their lives. Consequently, these women went from one doctor to the next until they found one who verified their health problem and responded to their concerns with empathy and respect:

> We left that doctor's office because he was very rude and insinuated that all of this was my husband's fault. You know, something about didn't we know anything about birth control? Didn't he realize how bad my health was? We just got up and left.

> The problem started after my son was born, about when I went back for my six weeks check-up, and she just said it was probably because I had just had a baby and give it time, and I never really paid attention to it, but then I started getting my menstruations every week, so I kept going back to her. At first she thought it was a growth inside. It can go on to the womb, or it can go on anywhere. So they did an exploratory on me, and they found out that wasn't it. So then she said, well there's really nothing they could do. Just carry on and ignore it....She just kept saying "It's in your head" or "Don't worry about it". She said, "We could do a hysterectomy, but I don't think that's your problem. I think it's just you know you!" So I decided to go for a second opinion.

As they progressed in the *Stage of Disruption*, most of the women in this study became increasingly affected by their interactions with spouses and physicians. Spouses were gradually becoming either very concerned about their wives or very intolerant of the effects of symptoms and coping measures. Furthermore, in spite of the fact that the informants were continuing their interactions with significant women, they were also realizing that this lay management of their illness was insufficient to effectively address their health problem. Consequently, the women began to increasingly rely on their physicians to medically manage their condition.

The acknowledgement of the health problem by the physician and the recognition of the illness by the spouse were two factors which influenced the way informants coped and

viewed their illness during the later period of the *Stage of Disruption*. The outcomes resulting from the presence or the absence of one or both of these factors are explained below and summarized in Figure 6.

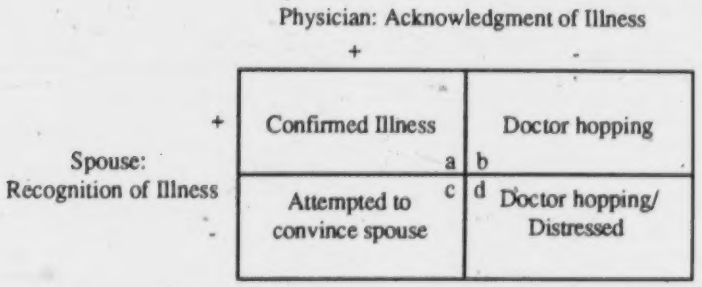

Figure 6. Influence of Spouse and Physicians on Women's Coping and View of Illness.

The women in this study successfully confirmed and labeled their health problem when physicians acknowledged their illness and when spouses provided emotional and functional support (Cell a). Informants in this situation tested a variety of medical options and felt supported by their spouses since they often assumed specific tasks in the home when these women were unable to carry out their normal activities.

When spouses did not recognize the illness in the later period of the *Stage of Disruption*, it became a priority for the women to convince them of their condition since symptoms were becoming more acute and increasingly difficult to manage (Cell c). Although physicians confirmed their illness, these women found the medical management of their condition difficult as their husbands were unsupportive during the implementation and testing of various medical options. Therefore, in order to obtain support and relieve the strain in their marital relationship, these particular women often used data resulting from diagnostic procedures as a means to persuade their husbands of their illness.

The informants became frustrated and began to search for a doctor who would listen and respond to their concerns when physicians failed to acknowledge their illness (Cell b).

In this instance, spouses supported their wives and often assisted them in their attempts to find appropriate medical assistance.

The failure to locate a doctor who would acknowledge their health problem overwhelmed the women when spouses did not recognize their illness (Cell d). In these cases, symptoms were becoming increasingly difficult to manage, and the informants had few means available to persuade their spouses of their illness. They searched for a physician on their own and viewed their situation as distressing.

Negotiating the Medical Management of the Condition

As the *Stage of Disruption* progressed, the women in this study became increasingly involved in the "medical management of their condition". The women perceived this form of management differently than the lay illness management provided by significant women. Most informants felt apprehensive during their encounters with physicians since they viewed doctors to be powerful and to possess expert and privileged information about the human body. In addition, the women were aware that doctors control the access to more potent medications and to a variety of diagnostic and treatment procedures. The perception of physicians as powerful created situations where most of the women felt disadvantaged when negotiating medical options to find relief and the cause of their health problem. A few of the informants felt confident about their understanding of the medical jargon and the medical system of care. In these instances, these women displayed assertiveness during their consultations with doctors. Most of the informants, however, often acquiesced to their physicians' suggestions with little or no negotiation as they had difficulty assessing whether an option was appropriate or not:

> So I told him I wanted a D & C [Dilatation and Curettage]. Maybe that will do it. He goes, "Well, sometimes it helps, sometimes it don't" He said, "But if you really want to take that route first and see if it helps, then we'll try it."

> I went to the doctor and she asked me all these personal questions about how you get along with your husband and all this stuff, and I said fine. I said other than sometimes we think about our finances, but that's normal in this day and age, everything else seems to be just fine.

> I'm working, my husband's working, no problems. So she checked me and everything, and she asked me where the pains were. So she started giving me antibiotics. She thought maybe it was an infection of some sort. So she gave me antibiotics, and the pains subsided for awhile, and then they came back again. And I kept going to Dr._____, and every time I would be going back to her, she would be giving some other medication. Then, she told me, "The only way that we're going to find out what's wrong in there is if you go for an ultrasound." So, I went for an ultrasound.

Over time, physicians and informants implemented, tested, and exhausted a number of medical options for controlling and diagnosing the health problem. In some instances, the women felt secure about the medical management of their illness, and they felt that a trusting relationship had been established with their doctors. In contrast, other informants felt less secure about the medical management of their condition. They said they did not know their doctors very well, and they were reluctant to verbalize many of their concerns:

> Well, sometimes when you don't really know the doctor that well, you're kind of nervous to ask all the personal questions. It's a little different if he's your family doctor and you've known him for years and you can joke around with him and whatever, like a normal person. Someone that you only see maybe once every two to three years or whatever . . . it's not someone that you can get really close to.

As the health problem remained unresolved, medical options became increasingly complex since more invasive procedures were being used to manage the symptoms and to precisely diagnose the health problem. Procedures such as a dilatation and curettage or a laparoscopy are examples of these particular options. Following these procedures, some of the women in this study were informed that abnormalities, such as, fibroids or adhesions, had been identified and were probably related to their symptoms. In other cases, however, no abnormalities were found, and as a result, these women often began to worry that an undiscovered malignancy might be the underlying cause of their health problem.

After testing these particular diagnostic and treatment measures, physicians began to introduce the option of having a hysterectomy. Unlike the previously tested surgical options, this form of surgical management did not allow for testing as it was irreversible. The women in this study reacted in a variety of ways when this option was presented.

Some reacted with shock and disbelief, while others felt overwhelmed by the irreversible nature of this surgery:

> I. He said, "There might be a few fibroids there. Sooner of later, it could be a year, it could be two, three, or whatever", he said, "but you're a candidate for a hysterectomy sooner or later."
>
> R. How did you feel when he talked about the possibility of a hysterectomy?
>
> I. Oh well, the usual snap reaction, "What are you crazy? I'm too young for that ain't I?" Cause to me I always thought a hysterectomy, that meant you had to go on these change of life and all that other stupid stuff. But then again, I was in pain off and on all the time, but I could still handle it.

The issue of having a hysterectomy was presented to the women in this study as the final option to consider in order to resolve their health problem. The women were informed by their physicians that a hysterectomy would mean removing the uterus and one or both ovaries if these should be damaged. Most doctors explained that they would attempt to preserve one or both ovaries since this would prevent the onset of menopause. One of the informants reported that she did not understand the meaning of preserving or removing ovaries and that her doctor was unclear about this issue:

> See, I really didn't understand a whole lot about it. I mean, I knew what I had to know about it, but as far as leaving one ovary and taking one, I would have just as soon they took them both. I don't know.

All of the women were told that this surgery would most likely alleviate their symptoms and that a hysterectomy would not negatively affect their sexual activities. Informants reported that physicians were very explicit about the fact that, except for this surgery, they could offer no other form of treatment to appropriately manage their condition:

> Well, he said, "There really is no alternative." He said, "There's no pill or anything to correct this. You know, we don't do this just to anybody. A hysterectomy is serious, so you should really think about it."

The Hysterectomy Decision-making

There was considerable variation in the way the women in this study made their decision to have a hysterectomy. One informant said her physician and her husband made the decision for surgery. In this instance, the doctor scheduled the surgery and did not give her time to make a decision. She discussed the issue with her husband on the following day, and she said that he responded rationally and objectively to the situation. He weighed the pros and cons of having a hysterectomy, and he quickly concluded that the surgery was the best option to pursue. This woman added that her husband did not consider her feelings and concerns about this alternative, and she felt distressed by his lack of attention to her emotional needs:

I. You know, it was like good points, bad points, stick it together and see what are the advantages and disadvantages of it and then decide on it . . . . I was nervous, I was worried. What about after the surgery? The pain or whatever goes with it for six weeks and, and terminating, also terminating the fact that I won't be having any more kids.

R. That was hard to come to terms with?

I. Myself yeah, —not that much with him.

One woman made her decision for surgery by herself. In this instance, her boyfriend and mother were excluded from the decision-making. She said that her doctor was very supportive and that she had a great deal of trust in his expertise. When the option was presented, she clarified her concerns and immediately agreed to have the hysterectomy. She felt confident about her choice, and she said she had a thorough understanding of the situation. Furthermore, she knew about the implications of this surgery since her mother had experienced it a number of years earlier:

R. So, was your mother the one who helped with making a decision about it?

I. Well, I had already made the decision. I had decided even before I left the doctor's office. I told him, "Yes, we will go ahead and do this because I don't want to go through the pain." And you know, it was getting to look like I was pregnant again with the swelling.

Some women in this study made their decision for surgery jointly with their spouses. In these instances, the physicians presented the option but did not participate in the decision-making. These informants waited as long as several months before making their decision, and they used this time to consider the implications of having or not having the surgery.

The hysterectomy decision-making was considered very painful by one woman and her spouse. Although they both agreed that living with the symptoms was unacceptable, they had difficulty coming to terms with the fact that the surgery would mean abandoning the goal of having one more child:

> My son is two now, he's not really a baby anymore. He's growing up on us and we sit back and we think, I don't remember him as a baby, and that took a lot out of him. He said, "You know, if things would have worked out, I would have liked another child." He didn't help the situation because he had the baby bug, too.

A few of the women began to favor the surgery alternative when they realized that they could no longer cope with their symptoms. In these instances, spouses expressed their opposition to the option since they worried that the hysterectomy would affect them sexually or that they might die from the surgery. These informants eventually convinced their husbands:

> He wasn't keen on the idea when I first told him about it back in November. He said, well right away the first thing was "No way, you're not going in for this surgery and so and so died from that . . . ." At the end, I had all kinds of thoughts. I even said to my husband a couple of times, "You know, something's growing in there and I probably have a tumour the size of a football." He didn't take lightly to that comment.

One woman, who felt very threatened by the hysterectomy option, consulted other physicians to confirm that this surgery was necessary to resolve her health problem. She had difficulty coming to terms with the idea of losing a part of her body. When she discussed the hysterectomy with her spouse, he immediately agreed to it since he was tired

of dealing with her illness. He did not respond to her fears and concerns and became insistent that she have the surgery. Consequently, this woman felt that she had little input in making the decision to have the hysterectomy. She coped with her feelings and her husband's lack of support by postponing the surgery until she felt ready to face it:

I. He didn't know about me cancelling out.

R. No?

I. No, I sort of made excuses cause he would phone and he would say, "Well did they call you today?" "No." I wasn't going to let him know . . . because he'd give me heck for it. But it was me that was going in, not him, and he would say, "Oh for God's sake, it's just an operation." Yeah right, you go in and have it for me then.

Other women in this study made the decision for surgery with the help of their spouses and physicians. In these instances, spouses were open to discussing the surgery, but they recognized that the women should make the final decision since the health problem and its resolution affected them the most. Physicians provided assistance by clarifying issues with the informants and their husbands. Consequently, these women felt well supported, and they felt that their input in the decision-making was important. One woman in this group postponed her decision for a time in order to have one more child. Most of these informants, however, chose to have the hysterectomy after deciding that they definitely did not want anymore children:

R. What did your husband think about this?

I. Well he said, "It's entirely up to you. If you don't want it, don't have it, but look at what you're living with now." He basically let me make my own mind up, and he said, "Whatever you decide that's fine." He felt that I should have it, but he said, "If you don't want it, you know, it's you going through it not me." No, he was quite supportive.

One informant let her doctor make the decision about the hysterectomy. She acquiesced because she was worried that a malignancy might be the underlying cause of her health problem. She had reservations about the option, but she felt that she would be at risk if she refused to have the surgery since she had been treated for cancer of the cervix a

few years earlier. In this instance, the spouse was excluded from the decision-making. Although he supported the physician's decision, he did not respond to his wife's fears and concerns:

> I. It was under the understanding that whatever they found, they took it out rather than wake me up and say we got to do this and cut me open again . . . .
>
> R. What was his [the husband's] reaction to all that?
>
> I. If it was going to make everything better, then go for it. Whether I ever went back to work or whatever, like, he didn't care. He just wanted the problem fixed.

Stage II: The Struggle to Preserve Wholeness

Managing the Separation

The women's preparation for their admission to hospital marks the beginning of the second stage of this process: the *Struggle to Preserve Wholeness*. At this point, the women in this study became actively involved in minimizing the effects of their imminent departure from the home on their spouses and children. Informants made arrangements with extended family members or close friends to provide support and assistance to ensure that family needs would be met during their absence, and a few of the women in this study enlisted the services of homemakers from a community agency. For some of the informants, managing the separation from the family also included the implementation of additional measures, such as, assigning specific tasks to older children, preparing and freezing meals, and, most importantly, providing emotional support to children by explaining to them the reasons for the hospitalization. The women implemented these particular strategies so that their families would remain as undisturbed as possible.

In addition, the women in this study also provided emotional and practical support to their husbands to preserve the integrity of their marital relationship. Most of the informants requested their husband's help in planning their departure from home. This involvement of spouses provided opportunities for the women for clarifying various aspects of family routines, such as, their children's extracurricular activities. Furthermore, during these

exchanges, the informants were able to assess the impact of their absence on their spouses' coping abilities. Several of the informants reported that their husbands were very concerned about their ability to manage the family on their own. In these instances, the women spent time reassuring their spouses. For example, they would attempt to put their absence from the home into perspective by emphasizing that their stay in hospital would probably be no longer than five or six days.

The management of the separation from the family continued throughout the women's hospitalization. The informants provided emotional support to their children by telephoning them as often as possible, while spouses were supported mostly when they visited them in hospital:

> I was separated from her [the oldest child] for six weeks when I was in there for my second one. I was on bed rest, and she thought I was going to be gone that long again. But I assured her not, four sleeps and one day you know. So she marked each day off on a calendar, and then I talked to her on the phone quite a few times so it wasn't like I was totally not around.

> I wasn't there with him, and I wasn't there with the kids . . . . As soon as he'd get to the hospital, that's the first thing he'd say, "I can't even sleep nights cause you're not there." He'd say, "Well, what are the kids going to do, this and and this is coming up and you're not there." I'd say, "Well, mom is there, she's going to be able to take care . . . ." Then, when he'd get ready to leave he'd say the same thing, "I just hate to leave you." I'd go, "Well honey, you've got to go home and go to bed you know . . . ." That separation did seem to have played a very big part with him and the kids, it did.

Becoming a Patient

The patient role was assumed by the women in this study when they were admitted to hospital. Most of the women viewed this role as disturbing and difficult. When they described their experiences as patients, the women focused on two particular aspects: (a) their lack of control and (b) their sense of fragmentation. The informants described lack of control in terms of their limited opportunities to initiate, to select, and to orchestrate events. Since they perceived the hospital as an unfamiliar setting, most of them felt uncomfortable and reluctant to please themselves or to make requests. Consequently, they most often

responded to requests. Furthermore, this sense of lack of control also emerged when the women discussed their limitations in engaging in specific self-care activities, such as, pain control:

> It [the admission] was around lunch time, so they got me a meal first thing, and then they showed me around the unit, which I was glad for because I was scared to go out cause I thought I might get lost if I wandered around . . . . Then they told me what to expect and what was going to happen and everything.
>
> It's frustrating when they give you something for pain and it doesn't take the pain away. You can't have anything for four hours. At home, I just take some more Tylenol®.

The informants described their sense of fragmentation as the perception that health professionals were recognizing their illness and organs, but were not recognizing them as individuals first. The women's sense of fragmentation was illustrated in their description of various hospital procedures. For instance, health professionals were described as focusing on specific body parts and functions or on specific tasks, such as, taking the history, without necessarily recognizing the women as individuals or attending to their needs:

> When the intern came in to take a history, I told him, "I don't know what's wrong." I said, "Could you please ask him [the gynecologist] if he can do a tubal instead . . . ." He said, "He would do a hysterectomy because I wasn't planning any more kids . . . ." I just didn't know anything about the side-effects or what happens once you have this done, so I was worried you know . . . . They were preparing me for the surgery but not with the information about what it is.
>
> At one point, the one she was an intern and she come in and she kept asking me these questions about breast cancer and stuff like that and looking at me like I was nuts. And then she said, "Well, you're in here to get a lump removed from your breast aren't you?" And I said, "No".[laughter] I didn't need to hear that . . . . She said, "Well, we must have you mixed up," and I thought, "You do the right operation!" [laughter]

Some differences related to the ways in which the women assumed and viewed the patient role emerged as they described their experiences. These variations were dependent

on two factors: (a) the women's knowledge of the purpose of hospital rituals and (b) their mastery of medical language. In this context, the term "ritual" comprises procedures which served to prepare women for the surgical event as well as the routine nursing care interventions carried out during the postoperative period. Being examined by health professionals, receiving information about the surgery and its immediate effects, and giving formal consent for the hysterectomy were examples of hospital rituals. In contrast, the concept of "mastery" relates to the women's understanding of medical terminology and their ability to utilize medical terms in their interactions with health professionals. The outcomes resulting from the presence or the absence of one or both of these factors are described below and summarized in Figure 7.

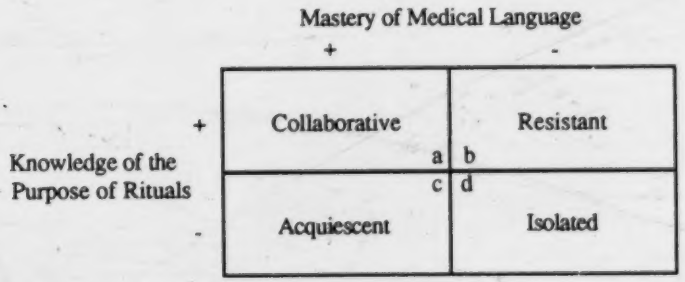

Figure 7. Women's Perceptions of the Patient Role.

The patient role was described positively when the informants mastered the medical language and had a good understanding of the purpose of hospital rituals (Cell a). Only one woman in this study described her patient experience in positive ways. In this instance, the woman said she felt in control and that she collaborated willingly with hospital staff. She added that prior to her hospitalization her physician had been very thorough in explaining what would happen during and after the surgery. She said that he often clarified and defined the medical terms used to describe procedures, body parts, and functions, and

specific events that occurred in the hospital. Consequently, she asked few questions while in hospital since most of her concerns had been explored and clarified by her physician before her admission. Furthermore, this woman had been admitted to the same hospital unit a few months before her admission for the hysterectomy. She remembered and knew the rituals, and she said that the staff members remembered her. She felt that the health professionals were concerned about the well-being of her whole person, and therefore, she experienced no sense of fragmentation:

> The staff there were excellent. The nurses were excellent, you know, the doctor and his staff . . . . That was the ward I was on six months ago, so I already knew all the nurses and most of them remembered me . . . . You know, I felt like I was at home.

Most of the women in this study described the patient role as uncomfortable or disturbing. Some of these informants had a good mastery of the medical language, but they were unclear about the underlying purpose of specific rituals (Cell c). For other women, however, the situation was different in that they had a poor mastery of the medical terminology but knew and understood most of the rituals and their purpose (Cell b). In both instances, these women felt that they were partially in control of events since they understood either some of the medical language or the purpose of most rituals. They tended to feel confident about their knowledge, and they asked health professionals questions in an attempt to deal with their concerns.

Both groups of women experienced a sense of fragmentation during procedures, but the factors which gave rise to this perception were different. Those who mastered the medical language described their fragmentation in terms of feeling ill at ease with rituals that they perceived as demeaning (Cell c). Furthermore, as these particular women relied on health professionals to guide them through hospital rituals, they were careful not to jeopardize their relationships with them. Consequently, they often acquiesced to their requests and refrained from verbalizing about aspects of procedures that they disliked:

> I understand that years ago the procedures were that there always had

> to be a woman nurse present, and now it depends on the doctor . . . . I still think, you know, even if you were to ask me I probably would be so embarrassed that I wouldn't say, "Yes, I want a female nurse present . . . ." I think they should have a nurse there period, all the time, and you could state it before you go in on a sheet or something so you don't have to be confronted with the doctor or feel that you're embarrassing him or hurting his feelings or something.

One woman experienced a sense of fragmentation when she signed the consent form for the operation. When she participated in this ritual, she discovered that another physician was consulted to confirm the decision for hysterectomy. This ritual is a requirement in Canadian hospitals and applies to all women under 40 years of age who undergo a hysterectomy. The informant viewed this practice as particularly demeaning because it implied that she was "too young" to have the hysterectomy and, therefore, that she was unable to make a sound decision regarding the management of her health problem:

> And I had to sign that form because I was too young for the surgery and all these things I had to do. It was like I just didn't understand anymore, like you had to have another doctor's signature because I was under 40, and I really felt like, God, I'm 12 years old, like, I'm not suppose to be having this surgery! It was very hard, I just felt like everybody was looking at me like this little girl is in for this surgery that she's too young for. You kind of got that impression, and I felt the nurses did. They babied me almost.

In contrast, those women who knew and understood the rituals and their purpose expressed their fragmentation in terms of being frustrated when health professionals discussed their condition and used a terminology that they did not understand or when staff members failed to respond to their needs (Cell b). Unlike the women of the previous group, these informants attempted to resist those aspects of hospital rituals that they disliked. They often verbalized about them to staff members and requested that certain changes be made:

> The morphine did nothing for me, it made me wide awake, and I told them three or four times. You know, you'd finally fall asleep and you'd feel another needle going into you. They didn't even ask you, so finally I said, "No more, give me a 292® or something." That I wasn't impressed with, the way they push drugs on you, take it, keep taking it, you know. It will make you feel better. It didn't help me at

all. I was really turned off with that.

Some of the women in this study described their patient experience in negative ways. For instance, they had difficulty understanding the medical terminology as well as the purpose of most rituals (Cell d). These women viewed themselves as having no control over events in the setting, and they experienced an acute sense of fragmentation. They were reluctant and embarrassed to clarify issues with health professionals since they were unsure about the questions that they could or should ask as well as how and when to ask them. They acquiesced to requests from health professionals and coped with their feelings by limiting or avoiding interactions with them as much as possible:

> Nobody told me anything, they would just come in and give me a shot for the pain and that's it. Nobody talked about anything . . . . I felt like I shouldn't be there . . . . I would feel hesitant to push the buzzer. After the second day, I felt like I shouldn't push the buzzer unless I really, really needed it.
>
> They asked me to sign some forms, and I didn't know what that meant. They didn't answer me, tell me anything unless I asked them. And I'm shy, to a point, and I didn't know what to ask them. I didn't know what to expect or anything, so I didn't know what to ask them . . . . They use such big words and medical terms.
>
> I was scared. I don't like to be alone, but I got a private room. I just didn't want to see anybody else, if that makes sense.

Some of the women in this study viewed the request that spouses leave the room during specific procedures as unacceptable and problematic and increased their feeling of isolation. The women considered this request to be unreasonable and unwarranted in those instances where physicians wanted to conduct a physical examination or when nurses wanted to perform interventions, such as, giving an injection for pain or changing a dressing. They said that this practice prevented them from receiving support and that it limited their attempts to manage their separation from their spouses:

> They were several young male doctors that came in to examine me, and each time my husband was there they would ask him to leave. And I did not know this till later, but that annoyed my husband very, very badly . . . . And you know, since then there's been a few comments from some of the friends, and it seems like most of the men would

> have felt the same way. They don't like the fact, you know, when it comes to that part, there just seems to be such a bond in there between a husband and a wife. It's almost like amputating part of you when you do that. Even though there's nothing physically happening to the husband, it affects him. If they're not let in on how to help you feel better, you feel like you can't get well because you have that problem of how am I going to make him understand. So that was very annoying.

During the hours preceding the hysterectomy, the women thought about their surgery and focused on one or more of the following four aspects: (a) the body's reaction to the anaesthesia, (b) how health professionals would handle their body, (c) the possible discovery of a cancer, and (d) what would be removed and what would be left intact inside their body. Furthermore, they also considered some of the possible long-term effects of the surgery. Mental, emotional, and sexual changes, hormonal instability, and changes in relationships with significant others are examples of the future implications of the surgery that the women reflected on at this time:

> I was worried of literally dying, but I was also afraid that they might find cancer, and I was also concerned about my ovary and tube and how they would handle the hormonal imbalance. I was afraid of how I would react, whether there would be a mental change. Would I be really nervous or yelling or screaming or all these things that you hear? And I was also concerned about how this would affect a married life sexually.

Immediately following the hysterectomy, the women in this study experienced sudden, severe physical symptoms, such as, pain, nausea, and vomiting. These women reacted to the intensity of their symptoms by focusing on their bodies. As a result, their ability to cope with the outside world was markedly decreased. They required assistance from significant others and health professionals to carry out simple activities, such as, sitting at the bedside. Although all the informants expected the occurrence of most symptoms, the feeling of being extremely vulnerable was an unforeseen emotional component.

All of the informants viewed anaesthetic agents and narcotic analgesics as substances which intensified feelings of vulnerability and loss of control. These substances changed

the natural rhythm of the body by creating disturbances, such as, altered sleep patterns. In addition, the women said these substances altered and impeded their ability to perceive and interpret reality. The informants attempted to minimize side-effects as much as possible since their occurrence prevented them from accurately assessing their bodies and their environment.

Some of the women in this study tolerated side-effects as they realized that the administration of analgesics would decrease over time. In contrast, other informants attempted to moderate side-effects by requesting that intramuscular analgesics be discontinued and substituted by less potent medications taken by mouth. In these cases, the women felt that it was easier to cope with the pain than cope with the side-effects:

> I'm very confused about what happened there. When you're in a hospital, they have you so doped up that you don't think of asking the doctor different questions when you see him. On Saturday, I finally just asked them, I just told them, "Don't give me any more Demerol®" because I just felt like I wasn't thinking anymore. I don't like the out of control feeling, so they were very nice that way, they took me off of it. I was still in pain, but I thought I could deal with that a lot easier.

Informants felt reluctant to discuss the side-effects from analgesics with health professionals. For example, one woman said that morphine affected her sleep pattern, producing nightmares in which she experienced the sensation of falling. After one particularly unpleasant nightmare, she told a nurse she needed to be held because she was afraid. In this instance, the nurse did not acknowledge her distress or attempt to reassure her in any way. This woman felt embarrassed and inappropriate by this disclosure of her feelings and was confused and angered by the nurse's reactions. She added that she did not attempt to talk about feelings resulting from her nightmares again.

The women described how medication side-effects affected their ability to understand information. For example, physicians most often provided information about the surgery during the first days following the hysterectomy, the time when side-effects

from medications were most acute. Consequently, the informants had difficulty making sense of what was being explained to them and had to seek clarifications at a time when side-effects were at a minimum:

> What I didn't like was that when I first came out of surgery . . . I remember him [the Doctor] vaguely telling me what kind of took place, and I expected him to come and retell me and explain to me, and he didn't. As a matter of fact, if I hadn't asked, I think maybe two days later, I wouldn't have really known, and that bothered me because I really wanted to know what happened, what was done to my body.

All of the women in this study openly discussed physical symptoms with health professionals. This was a strategy that the informants used to understand what was happening inside their bodies. The informants said that the health professionals were supportive and presented information about the frequency and cause of particular symptoms. For example, nurses explained to some women that the unpleasant feeling that "your insides were going to fall out" when standing up was, in fact, a normal common sensation during the first few days following a hysterectomy. They reassured informants that this would gradually subside.

Uncontrolled bleeding and bladder infections were the two complications that were most frequently reported by informants. Some women reported that uncontrolled bleeding occurred during the immediate post-hysterectomy time period. In these instances, they became very anxious and concerned. They felt that they were losing control of their bodies, and they were afraid that surgery might be necessary to resolve their problem. This complication was successfully resolved by the administration of several blood transfusions. One woman said she was very apprehensive about receiving blood as she was afraid of contracting the Acquired Immunodeficiency Syndrome (AIDS) virus. In contrast, those informants who experienced bladder infections were concerned about their problem, but they did not feel threatened by it as they had experienced bladder infections before undergoing the hysterectomy. These women received antibiotics to resolve this complication.

Significant others were disturbed by the changes in the behavior of women and by the unfamiliar equipment present in the hospital environment. They coped with their anxiety by talking with informants and also by touching them. Touching behaviors were used most often when women were experiencing severe physical symptoms:

> I remember the day of the surgery, as much as I remember. I remember my mom being there, and she kept wiping my brow with a wet cloth cause I told her I didn't feel good. I kept saying it really hurt, and she was the most, she was your typical mom. She was there rubbing me and always touching me and making sure I was okay, and I know at one point I looked up to her, and I guess I must have looked really terrible because she looked at me and she just started crying. It was really sad.

As the physical symptoms subsided, the women gradually regained physical strength and autonomy. They required less assistance to carry out daily activities, such as, bathing and walking. The administration of analgesics was also gradually decreasing, reducing the side-effects. Informants were now able to think and to relate to their bodies and the outside world in a known, ordinary, and normal fashion.

Observing the Changes

At this point, the women spent time considering the finality of their choice of having a hysterectomy. They expressed relief that the unacceptable life-style and the hysterectomy were now behind them. They also experienced a sense of grief. The meaning of their grief did not center on one specific factor, such as, the absence of the womb, but comprised many aspects of their lives. The issues of infertility and intimacy with the spouse were aspects which increased the informants' grief as their consideration generated a sense of loss and uncertainty about the future. In contrast, the ability to be productive in the workplace, and the ability to cope with family and marital relationship demands were aspects which "balanced" the grief experience since the women's inner deliberations about these particular issues generated a sense of hope.

The women began to resolve their grief by exploring aspects related to the surgery as well as the long-term implications of the hysterectomy. This strategy helped the women to

come to terms with the surgical event. The presence or absence of cancer and information about organs left intact or removed were issues examined by all of the women. However, the informants had difficulty obtaining information about how their bodies reacted and how they were handled during the surgery. Physicians generally did not elaborate on these issues. The women thought this information was important since it could clarify and explain particular physical symptoms. For example, one informant asked her physician why she had such pain in her mouth following the surgery. He explained to her that her body had become very tense when the anaesthesia was first induced and that she had unknowingly bitten her tongue.

In addition to explaining particular physical symptoms, knowing how their bodies reacted and how health professionals handled their bodies represented information which reassured the women. Although their loss of control had been complete, this knowledge confirmed that the health professionals had remained vigilant, respectful of their bodies, and in control of the surgical event:

> It's not so much the part of losing something as it is, you know, not really knowing exactly what they're doing to it, and it's odd. You don't really think about that till it's starting to happen, and then you realize it. You want to know. You just feel odd just turning your body over to somebody. I knew that I had given them permission to do whatever they felt was best for my health, but you expect them to tell you afterward, and let you know exactly what happened.

Information about aspects of the surgery helped women anticipate the occurrence of particular long-term consequences, such as, hormonal instability. Furthermore, the manner by which such information was communicated to them as well as the reactions of significant others influenced how the women viewed themselves after the surgery. The informants experienced the sense that they were less than ordinary women when they thought that health professionals and significant others were acting indifferent:

> I said, "How was everything?" And that's when he told me that he had to take everything. He didn't tell me what was really wrong. He didn't tell me what the size was or how everything else was inside, nothing. He just said, "We had to take it all [the uterus and ovaries]."

> And I don't think that's very fair. I mean, it's my body not his. I was depressed that they had to take it all, but I think I was more upset about the way he talked to me about it. I mean he's a good doctor and I'm not really having any problems, you know. It's just that to me, it just seemed like I was a number, an assembly line thing, and I don't think doctors should be like that.

As the *Observing the Changes* phase reached completion, the women prepared themselves for returning home. Some of their concerns about the future were clarified, while others required a waiting period and clarification at a later point in time. For instance, women worried about their ability to enjoy sex and this could not be immediately resolved as they were told to wait up to six weeks before resuming sexual activities.

Written and/or verbal instructions about activities to avoid in order to ensure a prompt return to a healthful state were given. Generally, the informants did not view written information as meaningful. The application of some of these instructions was considered unrealistic by many women, especially those with young children and those who had little help in the home. On the other hand, verbal instructions were considered useful since there was opportunity for verbal exchange and clarification.

Listening to or reading the body to determine what to do or not to do was considered positive and helpful advice. Some physicians instructed a few of the informants in this way. These women found this information useful since their physicians were encouraging the application of a known, ordinary pattern of behavior to promote recovery.

Stage III: The Recovery

Adjusting to Changes

After their discharge from the hospital, the women in this study returned to their homes and began to focus on returning to normal. The presence of physical limitations, such as, abdominal tenderness, constipation, and fatigue, needed to be managed and resolved in order to secure a sense of autonomy and independence. Strategies that these women used to enhance healing involved: frequent rest periods, the reestablishment of known bowel and bladder patterns, appropriate nutrition, a gradual increase in activities,

and the delegation of tasks to others.

The women measured healing by observing the body, comparing the body to others, contrasting the present body state to its preoperative state, testing body tolerance to a gradually increasing rate of activity, and evaluating body reactions. As they engaged in these measurement activities, the informants focused on specific areas and functions of their bodies. The abdominal area, the incision line, points of insertion of foreign objects, such as, intravenous and intramuscular injection sites, along with bowel, bladder, sleep, and appetite patterns were the areas and functions that were specifically observed and assessed.

Over time, most of the informants began noticing positive changes in their bodies, such as, weight stabilization, weight loss, a flattened abdominal area, a fading incision line, bladder control, and the absence of presurgery symptoms, such as, an increasing level of energy, and a higher tolerance to stress. The women felt "good" about their bodies and had a greater sense of freedom, especially when changes extended beyond known boundaries of normality:

R. Do you still have those mood swings?

I. No, oh I still got my same temper and everything, but something really has to happen to get me in a bad mood. Like before, it didn't take nothing, I just switched from one mood to the other with no reasoning, no nothing behind it, so that plays on your mind, too. You think you're going crazy.

In contrast, some of the women in this study noted negative changes in their bodies. When complications occurred, women could not reestablish a normal life. Instead of freedom, they felt restricted by their bodies:

> Everybody was telling me, "Six weeks you'll be feeling great." Well, six weeks have come and gone a long time ago, and I'm still not in control of my body, and I think that's part of my anger right now. I'm angry because I'm supposed to be feeling better. This is supposed to be all over with. Now this lump again has got me scared, and I feel like I'm still out of control, and I just don't know when it's going to stop.

Informants felt positively about their hysterectomy when their health continued to improve. A steady improvement confirmed that the decision to undergo surgery had been the right one. In contrast, when complications occurred and when pressures to resume roles were high, the women in this study questioned the decision to have a hysterectomy. In these instances, these women thought the pace of improvement was too slow, and they doubted their decision.

Increased pressures to resume roles as well as low access to support resources limited the application of strategies to promote healing. Husbands who did not assist with household tasks and were absent from the home due to work, as well as limited assistance from extended family members and friends, prevented women from implementing and maintaining strategies to heal their bodies.

Women with young children were more limited in their attempts to promote healing than women with older or without children. Mothers of young children were reluctant to delegate the care of their children to others, and they often resumed care-giving as soon as they returned home. Children's sleep disturbances, increased irritability, reactions from perceived rejection, and increased demands for touch, attention, and affection were described as resulting from their time in hospital. These women experienced a conflict between using time consuming self-care strategies to promote healing and giving time to their children to compensate for their absence:

> Like the other day, he hit the corner of the heat register there and he cut his little head open, and I mean, people say don't lift him up! But I think that was half my problem cause I lifted my son way too early, but they don't understand, like, how can you say no to a two year old?

Informants with older children experienced this conflict with less intensity than mothers of small children. Older children had a greater understanding of the situation, had more independence, and imposed less demands on their mothers during this phase. They demonstrated concern by being more cautious when touching their mothers. Finally, they

provided support by assisting with tasks in the home.

Although most of the women saw steady improvement in their health after a few weeks at home, they also experienced times of frustration, boredom, and anxiety. They had control in delegating tasks to others, but they had little control over how tasks would be carried out. Family members did not necessarily perform activities in the same manner as these women wanted them to be carried out. Significant others sometimes justified themselves by criticizing how the women wanted things to be done around the home. These situations were frustrating, and the informants became impatient to resume full management of the family.

Promoting healing involved resuming roles gradually. As a result, the women had to alter normal patterns of activity during this phase. They had to find new ways to fill the days and manage their boredom. Being bored motivated them to carry out activities which would minimize this feeling and, at the same time, promote healing. The informants found it difficult to achieve a balance in these areas, and significant others did not always understand the purpose of their activities:

I. You see, I cleaned the car last night because I wanted to be outside, yet I didn't want to just sit out there. Like the other day, this is really scary, I weeded my deck.

R. You weeded your deck?

I. There was little weeds growing out of the cracks. I weeded it. My mom phoned me that night. "What were you doing today?" I said, "Weeding the deck." "Have you been smoking something? Were you smoking those weeds?" I said, "No mom." She said, "Why did you weed your deck?" I said, "Because it needed it." My mom really thinks that the doctors took something out here [points to head] when they were down there. It's like, "No mom, it's called finding things to do to keep my sanity," and that's exactly what it is. I know it is because I wouldn't normally weed my deck.

The women in this study found family roles harder to reclaim than roles in the larger community and workplace. In some instances, support resources were limited, and informants had to quickly resume roles within the family. But in other cases, assuming

normal roles was discouraged by family members as they had difficulty relinquishing activities taken on when the women were hospitalized. They questioned the readiness of women to resume their normal activities. These particular informants had to justify their readiness verbally or by other means:

I. I changed my living room around two weeks ago. My husband come home and just about shot me.

R. You moved all the furniture yourself?

I. Um hmm. The china cabinet was the hardest. He said, "Good Christ, it's been that way for years, it can stay that way." But I think it looks much nicer now, there's more room in it.

Community-based roles and roles held in the workplace were resumed with greater ease. The women did not reenter these roles until they had resumed their normal family activities. The informants reported that employers and individuals in the community demonstrated support by encouraging them to carry out activities at their own pace.

Resuming Sexual Activities

Anxiety about sexuality was experienced during this phase. Since the women had been instructed to wait approximately six weeks before resuming sex, they had time to reflect and worry about how they would function sexually. Although all of the informants had been informed of what had been removed from their bodies, most of them had difficulty conceptualizing sexual activities without a uterus. The informants were concerned about what happened to the desire for sex after surgery as well as what happened to the body space previously occupied by the womb.

Those women who had a close relationship with their physician coped differently with their sexual concerns than those who did not. Prior to the hysterectomy, all informants had been told that the sex drive and the pleasure derived from sexual intercourse would remain intact and might even be enhanced as presurgery symptoms would be absent. This information was sufficient to reduce anxiety for the women who had close relationships with physicians. In these instances, the informants completely trusted their

doctor and believed this information was true.

In contrast, the above information was not sufficient to decrease anxiety for those women who had not established a close relationship with their physician. In these cases, the informants questioned whether their doctor told them the truth about their sex life. Furthermore, these women developed a variety of beliefs about resuming sexual activities and about their bodies, such as, that sensations would be different for both the man and the woman as there would be an empty space inside the body, that pain was a possibility for the woman as remaining structures might be sutured together, and that the sexual drive could be decreased or absent as the uterus might in some way play a role in producing desire. These informants said they wished to know if their assumptions were correct; however, they felt embarrassed about specifically describing them to their physicians. Consequently, anxiety remained higher for these informants.

All of the women resumed sexual activities after a follow-up visit to their physician. The knowledge that healing was progressing as it should and that sexual intercourse could now be safely resumed reassured spouses since they had been concerned about causing pain or injury to their wives. Although all of the women still experienced various degrees of anxiety about their sexuality, they were pleased that the opportunity to confront it was finally at hand. By carefully and gently resuming sexual activities, informants were able to test for the existence of presurgery symptoms associated with sexual intercourse as well as previously identified concerns and assumptions.

Most of the informants reported that their fears and assumptions were unfounded. The women generally had positive feelings about their sexuality. They experienced pleasure during sexual activities, but they also perceived some differences in terms of sensations. Some commented that during penetration it felt tighter inside. Others stated that when penetration occurred, they could perceive a tender area in the lower abdomen, but they added that over time this particular sensation decreased. One woman reported that she experienced little pleasure during sexual activities and added that she was just happy that, at

least, there was no pain now. One other informant in this study expressed negative feelings about her sexuality. This woman was experiencing complications from her surgery at this time and remained anxious and concerned about her sexuality and her body. She said her level of energy and desire for sex were low and added that she did not feel sexy because she didn't like the way her body looked.

During the follow-up visit to physicians, information related to the examination and analysis of tissues removed during the surgical event were presented and briefly discussed. The physicians identified abnormalities, such as, fibroids, adhesions, cysts, and venous congestion, as probable causal factors of presurgery symptoms. In addition, all of the women were informed that no cancerous cells had been identified. This knowledge provided informants with a final confirmation that the choice for surgery had been the right option to pursue. One woman reported that her physician did not identify any abnormalities and stated that the uterus had been normal. In spite of the fact that pre-surgery symptoms were now absent, she was very disturbed by this information and experienced doubts about her decision to have a hysterectomy. Causal factors were not proposed by her physician, and she questioned the validity of her perceptions of symptoms.

Coming to Terms with the Hysterectomy

All of the women in this study attempted to come to terms with their hysterectomy by evaluating their recovery to reaffirm the decision for surgery. The strategies that women used to evaluate their recovery included: (a) monitoring the healing of their bodies, (b) assessing their energy level in resuming roles and activities, and (c) obtaining the doctor's expert opinion on their progress.

To come to terms with their hysterectomy experience, the informants also attempted to confirm two specific issues directly related to the decision for surgery. The first issue considered was the identification of the cause of the health problem. The informants sought to identify the causal factors of their illness during the follow-up visit with

physicians. The women were ensured that the decision for surgery was correct when causal factors were provided. The second issue that women examined was their level of input in the hysterectomy decision-making. The evaluation of this aspect was very important for these women as it enabled them to determine if the decision for surgery had or had not been their own. The knowledge that the decision had been their own established their competence in managing their health problem when the recovery was successful, and moderated the devaluation experienced when the recovery was unsuccessful. Variations related to the women's success in coming to terms with their experiences of hysterectomy are presented in Figure 8.

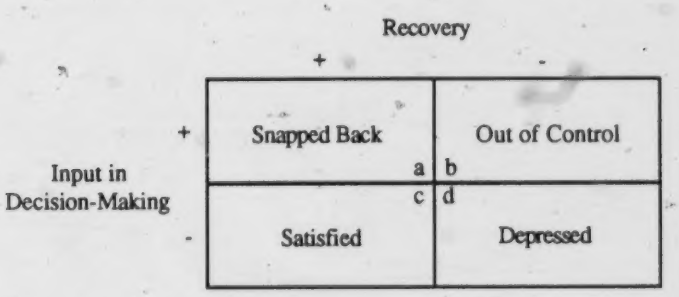

Figure 8. Women's Perceptions of the Hysterectomy Experience.

Several of the women in this study were successful in confirming their decision for surgery and in their recovery (Cell a). These informants were often surprised by how quickly they recovered. They felt that they had made the right decision and that they had dealt with their health problem in a competent manner. In these instances, their input in the hysterectomy decision-making was high. Furthermore, all of these women were well supported during their recovery. Consequently, they were successful in coming to terms with their hysterectomy:

> I zipped right through this one. I was sitting there the other day and I said, "Geez, it's been over two months boy and back in shape

already!" That worked out better than I thought it would.

> I think, geez you know, I can never have another one [baby] but for my health, I'm glad I did it. There's no regrets. I can really honestly say that I'm glad I did it.

> I recovered quicker from this than I did from my two C-sections.

Although one woman confirmed her decision for surgery, she experienced complications during the recovery (Cell b). These unforeseen bodily changes resulted in difficulties in managing the healing of her body and impeded her ability to maintain a sense of competence about her situation. In addition, maintaining a sense of competence was further hindered by the fact that she had limited support from her spouse as he often worked outside the city. She felt out of control and, in spite of her extensive involvement in the hysterectomy decision-making, doubted her decision to have the surgery. As a result, this woman continued to review this aspect of her experience. Furthermore, because she questioned her competence in dealing with her health problem, she also felt devalued as a person and expressed this sense of devaluation in terms of "not feeling like a woman." Consequently, this informant was unable to come to terms with her surgery:

> I feel like maybe I should have thought this through more. I did think it through. I thought I really talked it out with my husband. We decided this would be the best for me, and now . . . . Maybe what I did was wrong.

Other informants were successful in their recovery and confirmed that the decision for surgery was correct during the follow-up visit with their physicians (Cell c). In addition, they were well supported during the *Recovery Stage*. However, these women had very little input in the hysterectomy decision-making. Thus, they were unable to establish their competence in managing their health problem but felt satisfied that the right decision had been made:

> I did speak to a lady from another town that had it done and she said the same thing. She had pretty well the same problem as me, which was comforting to know. I think that was the first person that I'd talked to with the same kind of problem as mine, and she says the same as me, like she never regretted it.

One woman in this study had a successful recovery but could not confirm the decision for surgery (Cell d). In this instance, this woman had little input in the hysterectomy decision-making and was unable to confirm that the decision for surgery had been the right choice as her physician could not identify the causal factors of her illness during the follow-up visit. Furthermore, she was not well supported during her recovery. Like the woman who experienced complications during her recovery from the hysterectomy (Cell b), this informant was also unable to maintain her sense of competence about her health problem and continued to review the hysterectomy decision-making. Although her physical recovery was successful, she did not perceive it as such, and she was depressed about her situation because she felt that she had not assessed and dealt with her symptoms appropriately. Consequently, she felt devalued as a person and could not come to terms with her surgery:

> I feel so sad, I feel so empty inside you know. I feel I shouldn't I don't know. Towards my younger baby I feel like I have to stick with her all the time. It's just an unbelievable feeling. I never felt that way before.

A successful recovery and the confirmation of the decision to have a hysterectomy were events which signified that life was back to normal for the women in this study. However, those who could not confirm their decision and those who experienced an unsuccessful recovery were unable to come to terms with their surgery and did not perceive their lives as back to normal.

V. DISCUSSION

The purpose of this study was to examine the experience of women who undergo a hysterectomy. A qualitative mode of inquiry was used since an analysis of research concerning hysterectomy patients failed to provide a clear understanding and description of this experience. The findings of this study indicate that the process of establishing boundaries of normality is fundamental to the experience of women who undergo a hysterectomy. This process is comprised of three interdependent stages: the disruption of the body, the struggle to preserve wholeness, and the recovery. Establishing boundaries of normality is a basic social process accounting for most of the social and psychological variations in the experience of a hysterectomy.

In this chapter, specific aspects of the present investigation will be considered. First, issues related to the research method will be explored. Second, the findings of the study will be discussed. Finally, the implications of this study for nursing practice and nursing research will be presented.

Discussion of Research Method

Data Collection

During the course of this investigation, two interview methods were utilized to collect data. Face-to-face interviews were used with three of the women, while telephone interviews were conducted with the remaining seven informants. Although the use of telephone interviews was not anticipated at the onset of the study, the implementation of this method quickly became necessary as most of the potential informants that were encountered during visits to the host institution did not reside in the city. The utilization of these two methods to collect data served to enhance the investigator's ability to locate women who would be willing to participate in the study.

Several advantages were identified with each of the two methods of data collection. The face-to-face interviews provided the investigator with the opportunity to directly

observe the informants and the environment in which they lived. The women's facial expressions and body postures displayed their emotional state and served to emphasize their descriptions. In addition, the researcher's ability to observe their environment revealed information related to their life-style, their values and beliefs, as well as, their support system and coping abilities. Finally, this method also enabled the investigator to provide a direct form of support to the informants when this became necessary.

Telephone interviews were found to be very appropriate for eliciting women's descriptions of their experience of hysterectomy. The privacy and relative anonymity of telephone interactions appeared to facilitate and increase the disclosure of information related to sensitive issues. The women said they felt comfortable and were eager to speak of their experience. These interviews tended to have few interruptions and lasted longer than the face-to-face interviews. In spite of the fact that the researcher had no opportunity to directly observe these informants and the environment in which they lived, the telephone interview method was found to be particularly effective and well suited to the purpose of this study.

An investigation of this nature allows for theoretical generalizability. This particular type of generalizability refers to the applicability of aspects of the emergent theory to the experiences of other individuals. Theoretical generalizability is present when a grounded theory has "fit" and "grab" (Glaser, 1978). These criteria mean that the theory must be well grounded in the data and that it must make sense to other people.

The data collection methods used in this study may have affected the criterion of "fit" since researcher biases might have influenced the responses of the informants. The utilization of theoretical sampling and the constant rechecking of responses ensured that the potential effects of the researcher were minimized as much as possible. In addition, the initial reluctance of the women to discuss their experiences was reduced by means of multiple interviews. Repeated contacts with these women enabled the researcher to develop trusting relationships with them. As a result, these women were able to express their own

views and felt free to point out gaps in the emerging theory.

The criterion of "grab" was met through ongoing discussion with professional colleagues who were used as secondary informants. This sharing of information elicited responses, such as, "that's exactly how it was for me," which indicated that the findings made sense and were relevant to other individuals.

Limitations

Generalizability of the findings was not the goal of this study. No attempt was made to quantify any of the characteristics that were described since the sample size was limited to 10 women. The purpose was to identify the process of and variation inherent in the experience of having a hysterectomy, rather than to present information about the number of women who experience each response and to calculate statistical probabilities of outcomes.

Some limitations of the face-to-face data collection method were identified. During these particular interviews, it was observed that the women were often reluctant and embarrassed by describing and discussing intimate aspects of their lives. For example, their disclosure concerning the impact of the health problem on their sexual activities tended to be very brief. The women often changed the subject after a few minutes, and in some cases, their discomfort in discussing these issues was quite obvious as they had difficulty maintaining eye contact with the investigator. Furthermore, the frequency of interruptions was identified as an additional disadvantage of the face-to-face interview method. In spite of the fact that most encounters between these women and the researcher occurred in the evening, after children were put to bed, the interviews were often interrupted since the children noticed the presence of the investigator in their home and wanted to find out what was going on. Consequently, most of the face-to-face interviews tended to be short.

Discussion of Findings

Establishing the Boundaries of Normality

The basic social process of *Establishing the Boundaries of Normality* is fundamental

to the experience of women who undergo a hysterectomy. It refers to the development of a knowledge base which involves incorporating what is unknown into that which is known, ordinary, and familiar. This process was a means by which the women in this study understood and managed bodily changes resulting from their health problem.

A woman's confrontation with bodily changes set this process in motion as it prompted her to develop a frame of reference which enabled her to understand these changes. This frame of reference was crucial to the woman as it gave coherence to her experience of symptoms, and it oriented her actions. When actions implemented to manage bodily changes failed or when new symptoms appeared, the woman questioned and critiqued her interpretation of the phenomenon and shared her inquiry with other individuals. Thus, a new frame of reference was constructed which incorporated the experienced changes. In turn, this new frame of reference was tested through the implementation of a combined set of old and new actions to manage bodily changes.

Boundaries of normality were repeatedly established as new events and bodily changes occurred. In this way, a woman was able to "think on her feet" because she expanded, changed, constructed, and reconstructed her frame of reference while taking action to deal with her changing situation. This finding is comparable to the work of Schön (1983), who theorized that the development of knowledge involves a reflection which "tends to focus interactively on the outcomes of action, the action itself, and the intuitive knowing implicit in the action" (p. 56). This particular kind of knowing is also very much akin to the notion of improvisation. For example, jazz musicians listen to one another and to themselves when they improvise. They "feel" the music and adjust their playing accordingly. They vary, combine, and recombine a set of sounds stemming from a common frame of reference which gives coherence to their performance.

Belenky, Clinchy, Goldberger, and Tarule (1986) found that the development of knowledge in women involved the elaboration of a frame of reference primarily based on a personal acquaintance or a sense of connection to an object of inquiry. They added that this

particular way of understanding the unknown resulted, over time, in the establishment of a sense of mastery which was demonstrated through the women's purposeful actions upon the object of their inquiry. Similarly, the women in this investigation developed a sense of connection to their health problem by constructing a frame of reference which stemmed from their past experiences and the beliefs of their social group and which guided them in assessing their situation and in selecting and implementing coping measures.

The informants explored and addressed their health problem against the background of being normal. They related the idea of normality to a freedom from concerns about one's body, to a sense of being whole, and to the ability to conform to their social group's values, rules, and expectations. The informants viewed their illness and their hysterectomy as exceptional events which set them apart from other women. Furthermore, they thought their predicament was threatening as the risk of alienation and of being considered less than a person was implicit in their experience of bodily changes.

In his discussion of individuals who are at risk of social devaluation, Wolfensberger (1983) suggests that people "normalize" situations, such as, the experience of an illness or a surgery, by creating, supporting, and defending valued social roles. He adds that individuals at risk of devaluation elaborate valued social roles through the implementation of strategies which enhance their social images and personal competencies. In a similar manner, the establishment of boundaries of normality helped the women in this study to develop a sense of competence in dealing with their health problem, and it also functioned to preserve their dignity since it provided them with a means by which they could address and deny the false beliefs of individuals within their social group.

Furthermore, Wolfensberger (1983) emphasizes that a person at risk of social devaluation cannot support and defend valued social roles in isolation and requires assistance from significant others. The findings of this study support this notion as the successful establishment of boundaries of normality was contingent upon the provision of emotional and practical support.

The Disruption of the Body

In this study, the women's perception of illness was not based on the onset of symptoms alone. As the findings indicate, the recognition of the health problem was contingent upon changes in four specific conditions. The number of symptoms experienced represents the first of these conditions. The informants experienced symptoms for an extended period of time and were relatively unconcerned about them as most were isolated bodily changes. Angel and Thoits (1987) suggest that the recognition of a bodily change as a symptom rests on its occurrence as part of a constellation of abnormal changes. They add that an isolated change, unless it is incapacitating, tends to be readily associated to past experiences. In this investigation, the informants displayed a similar response as they often related their symptoms to their menstrual cycle.

In addition, the association of abnormal changes to one's menstrual cycle prompted the informants to view their symptoms as natural and inevitable occurrences because bodily changes resulting from the menstrual cycle are omnipresent in the lives of all women. This finding supports the notion proposed by Zola (1966), which states that the frequency of an aberration within a population delays its perception as a symptom. The informants began to concede that they might be ill when their symptoms increased in number or when they exacerbated to such a degree that they could no longer be ignored.

The perception of illness was also based on the variation of a second condition: the predictability and consistency of symptoms. In this study, predictability and consistency were necessary dimensions of control as the ability to anticipate the onset of symptoms and the stability of their characteristics enabled the informants to effectively manage their bodily changes. An effective control of symptoms impeded the recognition of illness because it reinforced the idea that these changes were natural and inconsequential. In contrast, the inability to predict the onset of symptoms and the inconsistency of their characteristics compelled the women to recognize their illness.

The degree of interference of symptoms with everyday activities represents the third

condition involved in the perception of illness. The disruptiveness of symptoms has been reported by several investigators to be one of the major factors involved in the recognition of illness (Apple, 1960; Bishop, 1987; McKinlay, 1981; Twaddle, 1981). In this investigation, the perception of a health problem was delayed when attempts to control symptoms did not impinge upon the quality of the informants' lives in unacceptable ways. The women remained unconcerned about their symptoms as long as they could continue to fulfill their roles within the family, the community, and the workplace.

Significant women's interpretation of symptoms represents the fourth condition involved in the perception of illness. This phenomenon has been described as a form of social sanctioning where members of a person's social network influence the ways in which particular symptoms will be viewed and attended to (Davis, 1984; Twaddle, 1981; Zola, 1966). Similarly, the findings of this study indicate that symptoms were not perceived as abnormalities when mothers, sisters, or close female friends advised the informant that her bodily changes were normal occurrences and a "part of being a woman."

Once the informants realized that a health problem existed, a systematic search for factors triggering the symptoms and for causes of the illness ensued. This exploration yielded data which enabled the women to better understand their problem, and it functioned to assist them in selecting, implementing, and testing a variety of coping measures to manage their bodily changes. These particular activities characterize the phase of *Learning to Read the Body*. These patterns of behavior have not been previously documented in investigations related to women's experience of a hysterectomy; however, similar frameworks are described in literature pertaining to the broader concept of illness behavior (Angel & Thoits, 1987; Dingwall, 1976).

Lazarus (1974) posits that cognitive appraisals and self-regulatory processes involving direct actions and palliative activities are key mediators of the person's reactions to the experience of an illness. Lazarus describes direct actions, such as, seeking information, as comprising activities which aim to master the illness experience as a

whole. In contrast, palliative activities, such as, relaxation techniques and analgesia, were described as consisting of modes of control which serve to reduce the impact of particular aspects of an illness and occur when direct actions cannot be maintained or implemented. The women in this investigation utilized similar strategies to understand and cope with their health problem. In addition, the implementation of measures categorized as palliative enhanced the informants' ability to cope with their situation for an extended period of time.

Although the women in this study initially engaged in the search for triggers and causes on their own, they gradually began to involve other individuals as their illness became increasingly difficult to manage. In this investigation, the husband was most often the first individual that a woman approached. The recognition of the illness by the spouse facilitated a women's ability to implement and test coping strategies and measure the impact of the illness on the marital relationship and on the family as a whole. This recognition of the problem resulted in the provision of emotional support, the clarification of perceptions, and varying degrees of practical support. The support of the husband was comforting and represented an affirmation of the personal importance of the woman. Thus, it served to enhance her self-esteem. In contrast, the lack of recognition of the health problem by the spouse limited the woman's ability to cope and tended to diminish her self-esteem.

Over time, more individuals were mobilized by the informants to address their health problem. This gradual involvement of others moderated their anxiety and functioned as a means to interpret and understand the illness experience. The informants utilized the beliefs of their social group as guidelines to interpret and evaluate their changing situation, to make decisions about what was wrong, and to determine the appropriate course of action. The role played by one's reference group in the experience of an illness is well documented in anthropological and sociological literature (see Angel & Thoits, 1987). A common view emerging from this literature is that the illness experience involves a negotiation between the sufferer and the group of reference which leads to the interpretation and labeling of the problem and guides the individual's decisions regarding the appropriate measures needed to

address the situation (Chrisman & Kleinman, 1983; Dingwall, 1976; McKinlay, 1981; Twaddle, 1981). The findings of this study support this view.

The consultation of members of the reference group allowed the informant to construct and validate an explanatory model of her illness. This activity implied that the woman jointly defined her symptoms with members of her social network so as to identify causes of the health problem which would limit the possible scenarios of coping strategies. A notion of explanatory models has been previously utilized in anthropological studies investigating the exchange of information between the ill person and various health care systems (Friedl, 1982; Nichter, 1981). In this study, the notion of explanatory models referred to the ways in which the health problem was articulated and discussed, and it was an important aspect in the establishment of boundaries of normality. These explanatory models created "public cases" out of women's private experiences of symptoms. In other words, an explanatory model rendered the illness experience intelligible to others and to the informant. Kleinman (1981) states that "explanatory models are not ways of thinking or systems of thought but practical statements about particular illness experiences. They are expressed guides to help seeking and clinical decision making" (p. 375).

As the informants sought and exchanged information with others, they also began to compare themselves to significant women within their social group. The exchange of information increased their understanding of their illness, while the activity of comparing themselves to others validated their perceptions of their health problem and protected their self-esteem.

Stewart (1989) provides further insight into the phenomenon of social comparisons with similar others by describing them as two types: (a) upward comparisons with others who cope more effectively than the ill person and serve as role models and (b) downward comparisons which enhance self-esteem and protection. The findings of this investigation illustrate the vital importance for the ill person to be able to carry out upward and downward comparisons with similar others. As shown in Figure 5 (p.41), the informants

who had a poor access to significant women experienced a sense of uncertainty or became distressed by their situation. The self-esteem of these women was diminished because they lacked role models through which they could increase their understanding of their health problem and expand their repertoire of coping strategies.

In a literature review related to the concept of social networks, Chrisman and Kleinman (1983) propose that a reference group consisting of numerous interconnected internal ties and regrouping homogeneous individuals receives less information flow from the larger society. They add that members of this kind of network tend to interpret outside events according to the beliefs of the group, which results in a high consistency in opinions and actions. In contrast, Chrisman and Kleinman state that social networks with loose-knit ties and comprised of heterogeneous people tend to receive a larger amount of information from the wider society as these individuals are better connected to social institutions. They say that members of these groups are also more independent in their approach to an illness episode, which implies less consistency in opinions and actions. The findings of this study support Chrisman's and Kleinman's analysis. The informants who had little access to significant women were members of loose-knit social networks and tended to seek medical help early on in the *Stage of Disruption*. In addition, these women relied heavily on the advice and assistance of health professionals to manage their illness. The informants who had access to significant women also consulted physicians, but they tended to do so at a later period of the stage as their illness was closely attended to by members of their social network.

The social network is seen to exert great influence in the ill person's decision to seek medical assistance (Eisenberg, 1977; McKinlay, 1981; Twaddle, 1981). This notion concurs with the findings of this investigation as the consultation of physicians was contingent upon the occurrence of a variety of positive and negative cues from network members and a woman's increasing inability to appropriately manage her symptoms. In some instances, significant others encouraged the informants to consult their doctor; in

other cases, negative cues, such as, the lack of recognition of the illness by the spouse, prompted the women to seek professional help. Still others were motivated to consult physicians because their bodily changes were increasing in severity and their husbands' tolerance of symptoms and coping measures was gradually decreasing.

The social situations resulting from the ways in which network members viewed and attended to the illness experience generated specific needs and expectations that the women in this study brought to their encounters with physicians. For example, the lack of recognition of the illness by the spouse prompted a woman to seek medical help primarily to convince her husband of the seriousness of her health problem and to enlist his emotional and practical support. In this instance, the woman's priorities centered on identifying physiological causes of her symptoms and on obtaining advice in managing the social and/or marital difficulties resulting from her illness. The needs and expectations that an informant in this kind of situation brought to a clinical encounter were vastly different from those of a woman who was receiving emotional support and assistance. This finding supports the notion that a health problem cannot be considered and addressed without exploring the social group and social situations into which it is embedded.

In a study exploring women's utilization of medical services, Gallin (1980) reports a similar finding as above in that women who lacked emotional and/or practical support consulted physicians not only to deal with their somatic complaints, but also to address their overall distress. Those women faced with social hardship expected that their doctors would assist them in managing symptoms and would advise them on the social and marital difficulties associated with their health problem.

Interestingly, Gallin (1980) also found that most women expected that their doctors would permit communication concerning the impact of their illness on the social and marital aspects of their lives. In a similar manner, the women in this investigation presented for care and readily verbalized about their somatic complaints. However, they generally did not elaborate on the impact of their health problem on the social and marital aspects of their

lives unless their physicians specifically elicited this information and demonstrated concern for their well-being.

The informants viewed the medical management of their illness differently than the lay management provided by network members. Most women perceived their physicians as powerful because they possess expert and privileged information and control the access to a variety of diagnostic and treatment procedures. Consequently, the informants often felt at a disadvantage in negotiating with their doctors about diagnostic and treatment alternatives.

The notion of power in medical encounters has been the subject of numerous discussions. The hierarchical physician-patient relationship, where the doctor is superior and the patient subordinate, has been questioned as to its benefits for the ill person seeking medical assistance (Donnell-Connors, 1980, 1985; Ehrenreich & English, 1973a, 1973b; Shapiro, Najman, Chang, Keeping, Morrison, & Western, 1983). Furthermore, the context surrounding the physician-patient encounter has also been an issue of concern. Zola (1981) contends that consulting a physician at his/her office results in the ill person's loss of power and security because the visit is held in an unfamiliar environment and involves assuming passive and embarrassing positions. These discussions have resulted in the promotion of an egalitarian approach to patient care which would facilitate the negotiation of treatment alternatives and increase the patient's power and security during routine medical consultations (Katon & Kleinman, 1981; LeBaron, Reyher, & Stack, 1985; Szasz & Hollender, 1956). The findings of this study support the promotion of an egalitarian approach to patient care.

The extent of congruence between a woman's interpretation of her illness and the physician's labeling and treatment modality also played a role in the woman's perception of the clinical encounter. Friedl (1982) reports a similar finding in a study exploring coal miners' lack of utilization of pneumoconiosis (i.e., black lung) treatment programs. Friedl found that the coal miners' interpretation of their illness was clearly at odds with the

interpretation and treatment plan of health care providers who worked within these programs. This lack of congruence resulted in the coal miners' dissatisfaction with clinical encounters and, therefore, accounted for the low utilization of treatment centers. Similarly, when the women in this study evaluated their encounters as helpful, they often expressed their satisfaction in terms which indicated a fit between their personal explanation of their illness and their physicians labeling and treatment plan. In contrast, a lack of congruence often resulted in dissatisfaction with care and in the women's decision to seek medical help elsewhere.

The Hysterectomy Decision-Making Process

The women in this study viewed the hysterectomy decision-making process as a difficult aspect of their illness experience because the implementation of this measure would result in a definite and irreversible loss of an organ and, for some, would also involve abandoning personal and/or relationship goals. Physicians presented this alternative as a final solution, a last resort, to resolve the informants' health problem and increase the quality of their lives.

In this investigation, there was considerable variation in the manner by which the hysterectomy decision-making process was carried out. Thomas (1977) identifies two modes of decision-making: (a) the analytic mode, defined as descriptive, accurate, and not exaggerated; and (b) the persuasive mode, which involves prescription, direct influence, and demands. In this study, there is evidence that these two modes of decision-making were utilized. In some instances, the persuasive mode was used mostly by the physician and/or the husband and rarely by the woman. Thomas considers this mode as dysfunctional in that participants fail to explore other alternatives or consider relevant information. The findings of this investigation concur with this analysis since relevant information, namely the woman's input, was, in some cases, suppressed or was dismissed as unimportant by the spouse and/or the physician. These women often felt that although the decision was supposed to be theirs to make, the doctor and/or the spouse were the

individuals who actually made the decision for having the hysterectomy.

In a study exploring the effects of stressful life events on the decision-making for surgery for obesity, Rand, Robbins, and Kuldau (1983) found that stressful events often provided the necessary impetus for patients to pursue the surgery alternative. Similarly, in this investigation, those women who described a persuasive mode of decision-making acquiesced to the hysterectomy alternative in spite of their low input in the decision-making. They believed that their current marital, familial, or social difficulties were exacerbated and, in some cases, caused by their health problem, and they hoped that the surgery would alleviate these stressful situations.

In those instances where the analytic mode of decision-making was used, the woman, the husband, and the physician were the individuals involved in making the decision for surgery. The role of each participant was clearly delineated. The woman's input had the greatest weight since the decision that would be taken would affect her the most. The spouse provided input and openly recognized that the woman had the final say in the matter. Finally, the physician's role in these cases was that of resource person. This mode of decision-making was highly effective and empowering for these women as they felt in control of the situation and respected by the other participants. Richards (1978) agrees with this decision-making mode and posits that the decision for an elective hysterectomy should be ultimately made by the woman. He adds that the provision of relevant information is also required because it ensures that the issues pertaining to the surgery and its consequences are clear for all involved in the decision-making process. The findings of this study lend support to this notion as the input provided by the resource person enabled the informant and her spouse to address their fears and misconceptions and increase their knowledge of the hysterectomy alternative.

The Struggle to Preserve Wholeness

The decision to have a hysterectomy served as a bridge between the known and familiar world of life within the family and community and the world of the hospital. Once

the decision for surgery was made, the informants began to manage their separation from their families. The implementation of management activities continued throughout the women's hospitalization, and this enabled the informants to maintain relationships with significant others. Moos and Schaeffer (1984) view the phenomenon of sustaining relationships with others as an adaptive task that the ill person carries out during his/her hospitalization. They focus on the fact that close relationships with significant others "help patients obtain information necessary to make wise decisions about their medical care, find emotional support for their decisions, and secure reassurance about the problems they face" (p. 12). The findings of this study provide a more dynamic perspective of this phenomenon in that management activities allowed for an exchange of support and affirmation between the informants and significant others. Thus, the women's implementation of strategies aimed at managing their separation from others represented a social role which enhanced their self-esteem and protected them from the devaluation implicit in "becoming a patient."

The women in this study perceived the patient role as devaluating because it involved a lack of control as well as a sense of fragmentation. Lack of control was rooted in the women's inability to initiate and orchestrate events. In contrast, fragmentation was related to the health professionals' focus on tasks or body parts and functions, with little or no attention given to recognizing the informants as individuals. The hospital rituals, which transform the ill person into a patient, have been shown to systematically divest the individual of his/her own dynamic resources (Bégin, 1987; Scheper-Hughes & Lock, 1987). In addition, it has been suggested that because written and verbal information given to patients include so much medical jargon it causes poor understanding and retention of data (Wallace, 1986), which further alienate the ill person (Zola, 1981). In this investigation, the women's perception of the patient role varied according to their ability to understand the purpose of hospital rituals as well as their ability to master the medical language. Limitations in one or both of these areas were found to accentuate the experience

of devaluation.

Wilson-Barnett (1979) suggests that the patient's participation in hospital rituals helps him/her learn that physical symptoms are of greatest importance to the staff and that needs will be most effectively met if they are communicated as physical complaints. In a similar manner, the women in this study readily discussed their physical symptoms, but they were reluctant to directly express their thoughts and feelings about their situation to health professionals as this placed them at risk for further devaluation. The women's thoughts and feelings about their situation were most often not expressed or expressed indirectly, in terms acceptable by the staff. This particular finding provides further insight into the notion of fragmentation. The common view related to this concept is that when it is imposed by others fragmentation results in the person's alienation. However, in particular circumstances, such as those experienced by the women in this investigation, a person's deliberate establishment of separations can also be viewed as an effective coping strategy. In her analysis of the notion of fragmentation, Martin (1987) posits that "when external circumstances deny dignity to a person, letting only a portion of the self outside to be degraded is a form of self-preservation" (p. 18).

During the hours preceding the surgery, the women in this study reflected on particular aspects of the procedure and the possible long-term consequences of having a hysterectomy. The discovery of a cancer was a fear expressed by most of the women. Steptoe, Horti, and Stanton (1986) report that women who undergo routine noncancer gynecological surgery worry about gynecological cancer more than any other disease during the preoperative period. In addition, these investigators also found that concerns about gynecological cancer tend to be exacerbated in women with symptoms of a nonspecific nature. Similarly, in this investigation, those women whose symptoms had not been associated to specific abnormalities, such as, adhesions, tended to discuss in detail their fear of cancer with the investigator. In contrast, although those women whose presenting symptoms had been clearly associated to a specific abnormality also expressed

fear of cancer, they did not dwell extensively on this issue during the interviews. This finding suggests that fear of cancer may be a common concern for women who undergo elective hysterectomies.

During the time period following the surgical event, the informants focused on regaining their physical strength and autonomy. As these were gradually reestablished, the women began to explore their situation by considering the finality involved in having a hysterectomy. Although the informants were relieved that the surgery was over, they also experienced a sense of loss and grief. To cope with their feelings of loss and grief and prepare themselves to face the future, the women attempted to examine various aspects of the surgical event as well as the long-term implications resulting from their hysterectomy. The presence or absence of cancer and information about organs left intact or removed were issues that the women easily clarified. In contrast, information about how their bodies reacted and how they were "handled" during the surgery were aspects that were difficult to explore as health professionals generally did not elaborate on these issues. Obtaining this particular information was very significant for women because it not only explained certain postoperative physical symptoms it was also a means for the informants to enhance their self-esteem. The knowledge that staff members had been respectful of them at a time where they had lost all control was perceived as reassuring and represented an affirmation of personal importance.

Prior to their discharge from the hospital, informants received written and/or verbal instructions to assist them during their recovery and ensure their prompt return to a healthful state. Generally, the women viewed written instructions as unhelpful because no information was provided as to how they were to apply these measures to their particular situations. Women with very young children as well as those whose external resources were limited often considered some of the instructions to be unrealistic and very difficult to implement. In contrast, verbal exchanges with health professionals were viewed as helpful since the informants had opportunities to clarify their concerns and obtain information

regarding the operationalization of these measures. This finding suggests that instructions alone, whether written or verbal, are not sufficient to prepare a patient for discharge. Preparing a patient to return home should also involve exploring his/her internal and external resources and providing information to help the person plan the implementation of instructions at home. Despite the fact that this recommendation has been previously suggested by investigators and clinicians alike (Krueger et al., 1979; Wilson-Barnett, 1979; Zola, 1981), the findings of this study indicate that nurses and other health professionals have difficulty implementing this recommendation in the clinical setting. Krueger et al. (1979) posit that effective discharge counseling requires sufficient time for the health practitioner to perform discharge preparation activities adequately as well as an administrative climate encouraging the practitioner to engage in these activities with the patient. Considering the findings of this study, it is argued that these prerequisite conditions for discharge preparation should be seriously considered in order to correct the discrepancy between the ideal and the reality of clinical practice.

The Recovery

In this investigation, it was found that the women's social situations and the ways in which significant others supported them affected how the informants progressed in their recovery. Particular social situations, such as that of a housewife with small children, were identified as enhancing or impeding the women's ability to implement strategies to promote healing as well as their ability to resume roles at their own pace. Generally, mothers of small children experienced difficulties in maintaining activities to heal their bodies as they could not delegate the caregiver role to others. Young children tended to seek out their mothers to have their needs met as soon as these women returned home. In addition, these informants often experienced guilt and worry about the impact of their hospitalization on their children, and these feelings further prompted them to quickly resume care-giving. This particular situation accentuated these women's isolation from others because they were more restrained in their ability to access and communicate with significant women. This

finding is comparable to the work of Webb (1986), who found that various social situations affected a woman's recovery from hysterectomy. Furthermore, Webb also identified housewives as having particular needs for support and information because of their relative isolation from others.

The informants needs for support varied as they advanced in their recovery. For example, assistance with tasks in the home was a primary kind of support required at the onset of this stage. This need gradually diminished as strength and autonomy returned, but it tended to increase when the women experienced complications. In several instances, the practical support given to the informants was found to be problematic for two reasons. First, significant others were often limited in the assistance that they could provide. Husbands who were absent from the home due to work is an example illustrating this point. Second, problems were also encountered when the women's need for assistance and significant others' perception of this need were incongruent. In some cases, significant others expected the woman to resume full management of the home too soon during recovery. In other cases, significant others questioned the readiness of the woman to resume her roles and had difficulty relinquishing these roles. Lack of congruence between the woman's need for assistance and the significant others' perception of this need resulted in feelings of frustration and annoyance. This particular finding has also been reported by other researchers (Webb, 1986; Webb & Wilson-Barnett, 1983a, 1983b). The problems encountered by these women in relation to the social support provided during recovery justify the idea of informing significant others about the woman's changing needs during her convalescence.

Coming to Terms with the Hysterectomy

Evaluation of the recovery as well as confirmation and review of the decision for surgery represent the means by which the informants came to terms with their experience of a hysterectomy. The women evaluated the progress of their recovery on an ongoing basis by monitoring the healing of their bodies and by assessing their energy level. In turn, these

assessments prompted them to periodically review the decision for surgery. Their perception of the decision varied and changed according to their evaluation of their situation. For example, the women felt the hysterectomy decision was very appropriate if they observed consistent healing or if they noted positive bodily changes, such as, weight stabilization. In contrast, the hysterectomy decision was perceived negatively if complications occurred or if pressures to resume roles were high. In these instances, the informants felt that it was highly probable that the hysterectomy decision had not been the appropriate choice. In a study exploring the decision-making process for surgery of chronically disabled adolescents, Deatrick (1984) reports a similar finding and states that the adolescents continuously considered the decision for surgery throughout their hospitalization and during the postoperative period. She notes that the adolescents' view of the decision was modified by the experience of the surgery itself and by input from parents, staff, and other patients.

In this investigation, it was found that the women attached a great deal of importance to the follow-up visit with physicians because it was at this time that they determined the success of their recovery by measuring their personal evaluation of their progress against their doctor's expert opinion. Thomas (1977) identifies the evaluation of outcomes as an essential aspect of the decision-making process because it provides a means by which one determines if a problem has been successfully resolved or not. Furthermore, evaluating outcomes also incite the person to either go on with his/her life or attempt to decide on another course of action to resolve the problem. In this study, the evaluation of the recovery as successful was not sufficient to enable the women to come to terms with their surgery experience. Causal factors were also required to confirm and justify the decision for hysterectomy. This confirmation of the decision was sought during the follow-up visit. An unsuccessful recovery and the absence of causal factors resulted in feelings of devaluation and hindered the women from coming to terms with their hysterectomy experience. In contrast, women who successfully recovered and confirmed their decision

expressed satisfaction about their situation and considered their lives to be normal again.

The degree of input in the hysterectomy decision-making process was found to influence the women's perception of their experience (see Figure 8,p.71). For example, the sense of devaluation for those women who failed to identify a cause for their health problem and who had little or no input in the decision-making was more acute than that of women who experienced complications and had an extensive involvement in the decision-making. A similar pattern was also identified for those who felt positively about their experience. Self-esteem was greatly enhanced when the women's input in the hysterectomy decision-making process had been high as these informants felt impressed by their effectiveness in resolving their health problem. In contrast, women who recovered and confirmed their decision and had little or no input in the decision-making process expressed satisfaction with their situation, but they did not demonstrate an enhanced self-esteem. This finding further illustrates the importance for a woman to make her own decision to have a hysterectomy.

Implications for Nursing Practice

Many implications for nursing practice arise from this investigation. The most important is the recognition and understanding that we, as nurses, are part of an authoritarian, hierarchical, impersonal, and distancing health care system. The finding that women who undergo a hysterectomy experience fragmentation and loss of control illustrates the impact of such as system on the individual, and this should prompt nurses to examine their practice and their expectations of the hysterectomy patient. A failure to do so would negate the holistic premise on which the nursing profession is based.

Exploring the ways in which nurses assess hysterectomy patients represents a starting point. Nurses need to develop ways of assessing women who undergo a hysterectomy by criteria other than those of cure and treatment. This would allow for a more holistic view of these women as consideration would be given to recognizing them as individuals. Furthermore, a holistic assessment would also involve an inquiry into their

external resources and the social situations in which they live. This broader perspective of assessment would most likely foster the establishment of a stronger bond between hysterectomy patients and nurses. In turn, a stronger bond would also enable nurses to be more effective in meeting the needs of these women.

Changes in the ways in which nurses give care, support, and information would logically follow from the establishment of a holistic view of hysterectomy patients. Nurses can and should play a special role in helping women cope with the fragmentation and loss of control implicit in becoming a hysterectomy patient. There are many concrete strategies that nurses can implement to empower these women. Examples of these are provided in the remaining part of this section.

Allowing women decisional power over the manner by which hospital rituals are carried out represents one way that nurses can minimize loss of control and fragmentation. For example, a woman should be provided with the opportunity to decide if the presence of a nurse is required during particular rituals, especially during physical assessments by physicians. As the findings of this study indicate, it is wrong to assume that all women feel comfortable and secure when doctors examine them. Furthermore, it is not sufficient for nurses to address this issue before the start of a doctor's physical examinations as women often feel intimidated by the presence of the physician(s) and will refrain from speaking their minds. As one informant suggested, it would be more appropriate to clarify this issue in writing as soon as women are admitted to the hospital.

The role that nurses should play during a physician's physical assessments should not be that of the innocent bystander. If a woman requests the presence of a nurse, it means that the nurse's active support is clearly required. Nurses can effectively assist women to empower themselves by transforming this ritual into a learning experience. While the doctor learns about the woman, the nurse can play an important role in translating what the doctor is saying into meaningful information for the woman, thereby assisting in her learning. This kind of intervention represents a recognition of the hysterectomy patient

as a person and would effectively assist her to feel more comfortable in voicing her questions and concerns to physicians.

A second area where nurses should foster women's decisional power concerns self-care activities, namely, pain control. The women in this investigation often expressed annoyance about the fact that they had little or no control over the administration of analgesics. Nurses were most often the individuals who decided when women were in pain and, in the immediate postoperative period, regularly administered intramuscular analgesics every four hours without asking the women if they required analgesia. This practice should be revised as it perpetuates the notion that nurses know more about the patient's needs than the patient herself. Furthermore, this practice tends to be perceived as demeaning by women and serves to accentuate their loss of control and sense of fragmentation.

The ways in which we provide information to the hysterectomy patient is another area requiring examination. Although nurses may perceive an elective hysterectomy as routine surgery, it is not perceived as such by women who experience it. As the findings of this study indicate, being hospitalized for an elective hysterectomy is an exceptional and stressful event for women. In acceptance of this finding, it should be recognized that information given about procedures, bodily changes or particular nursing interventions may not be completely understood the first time it is presented, especially if much medical jargon is used and if too much information is given in a short period of time. Information should be presented with a minimal use of medical terms and paced according to the patient's ability to assimilate the information. In addition, the information should be repeated if it was initially presented at a time when a woman was experiencing side-effects from analgesics. The implementation of these measures would greatly enhance the women's ability to process and understand information and decrease their loss of control.

Hysterectomy patients actively manage their separation from their families throughout their hospitalization. This management represents a social role that women

create to enhance their self-esteem and to sustain their relationship with significant others. Nurses can facilitate the patient's management activities by minimizing separations between the woman and her husband or family members as much as possible. The mandatory exclusion of the spouse from physical examinations and from routine nursing interventions, such as, giving an injection or changing a dressing, is a practice that should be revised as it may be perceived as unreasonable and create an impression of insensitivity. Instead of assuming that this exclusion practice is not problematic, nurses should clarify this particular issue with each woman.

Fostering communication with other women who undergo this surgery is another empowering strategy that nurses can use to assist the hysterectomy patient during her hospitalization. Hysterectomy patients may feel isolated in their predicament, especially if they have had low access to women who had this surgery prior to their hospitalization. This contact with similar others would allow women to carry out comparisons and exchange information and support. The knowledge that one is not alone in facing this event and that particular bodily changes are also experienced by others is reassuring and would increase the patient's comfort and sense of well-being.

The discharge preparation represents an additional area where nurses can have a significant impact on the hysterectomy patient. In this study, it was found that the implementation of discharge instructions at home is an area of concern for most women, and in light of this finding, nurses should consider a greater use of discussions with hysterectomy patients as verbal exchanges would allow for an accurate assessment of each woman's external resources. This measure would enable nurses to be more effective in addressing the concerns of women as they could assist them in planning the application of discharge recommendations at home.

The measures discussed in this section are not exhaustive; instead, they represent examples to illustrate how nurses can increase their effectiveness in caring for women who undergo a hysterectomy. It is hoped that these suggestions will incite nurses to identify

additional strategies of care to protect a woman's dignity and to enhance her control over her body during hospitalization for hysterectomy.

Implications for Nursing Research

This study provides a view of the experience of hysterectomy from the women's unique perspective. The findings have revealed common strategies that women use to cope, manage, and adjust to their bodily changes, and these strategies should be tested and explored by further research. In addition, the findings have also provided insights into a number of areas which should be considered in future investigations of hysterectomy patients in order to gain a more complete understanding of this experience. The notion of social support for women who undergo a hysterectomy represents the first important area for nursing research. The kinds of support women find most helpful and unhelpful, in particular social situations, at different stages of this experience are relevant issues requiring clarification. Nurses should also explore how to assist these women in obtaining the support they need. A second area where nursing research is required pertains to the impact of the health professional/patient role on the woman's ability to cope with bodily changes and on her perception of the hysterectomy. A third important area warranting further study concerns the information needs of these women. The kinds of information needed by different groups of women who undergo this surgery and the identification of effective methods of providing information to hysterectomy patients are examples of pertinent issues that nurses should examine in order to expand their knowledge base related to this experience.

Propositional Statements

Although the findings of this study are not generalizable, several propositional statements have emerged which should be tested in future studies. Some of these statements are presented below, and it is hoped that these will be of assistance to other investigators.

The propositional statements identified as a result of this investigation are:

1. The recognition of a health problem by the spouse and access to information and support from significant women delay women, who experience gynecological symptoms, from seeking medical assistance.
2. Communication and comparisons with other women who have successfully adjusted to their hysterectomy enable hysterectomy patients to cope more effectively with their bodily changes.
3. A lack of congruence between a woman's interpretation of her health problem and the physician's labeling and treatment modality negatively affects a woman's perception of the clinical encounter.
4. A lack of decision-making power during the hysterectomy decision-making process undermines a woman's sense of competence and control over her body.
5. Gynecological symptoms unrelated to specific physical abnormalities generate a fear of cancer in women who undergo an elective hysterectomy.
6. The power and control of health professionals are sources of stress and devaluation for hysterectomy patients.
7. Health professionals can increase the hysterectomy patient's self-esteem during her hospitalization by promoting a reciprocal exchange of support and affirmation between the woman and significant others.
8. Health professionals can increase the hysterectomy patient's ability to implement discharge instructions by assessing her external resources and helping her to plan the application of recommendations at home.
9. Hysterectomy patients with young children at home are more limited in their attempts to promote healing during recovery than women with older or without children.
10. The woman's ability to come to terms with the experience of a hysterectomy is contingent upon a successful physical recovery and the identification of causal

factors of the health problem which confirm the decision for surgery.

The processes described in this study of women undergoing hysterectomy may be evident in other chronic illnesses that reveal similar characteristics. For example, illnesses that must be recognized by the person, that have a slow and recurrent onset and dependent on patient report to the physician for the initiation of care (such as angina) may use processes identified in this study such as "Reading the Body". However, further investigation of other illnesses using grounded theory would be necessary to verify this proposition.

VI. SUMMARY AND CONCLUSIONS

This study examined the experience of women who undergo a hysterectomy. A review of the research literature concerning hysterectomy patients provided valuable information about this phenomenon. However, these studies brought to light that investigators tend to explore particular aspects of this experience which results in a fragmented body of knowledge. In addition, the review of these investigations revealed that researchers have not attempted to examine this experience from an emic perspective. Consequently, the grounded theory method was utilized to describe the hysterectomy experience in its entirety, and from the perspective of women. Interviews with hysterectomy patients between the ages of 24 to 39 years of age were the major source of data.

The findings of this study indicate that the experience of women who undergo a hysterectomy is a process which comprises three emergent stages: the disruption of the body, the struggle to preserve wholeness, and the recovery. As the individual progresses through each stage, she attempts to establish boundaries of normality. The hysterectomy patients' descriptions revealed that the establishment of boundaries of normality involved incorporating what is unknown into that which is known, ordinary, and familiar. Furthermore, it was found that the informants established boundaries of normality by developing a frame of reference which gave coherence to their experience of bodily changes. This basic social process enabled these women to understand their health problem, to remain in control of bodily changes, and to protect their self-esteem.

The first stage of the hysterectomy experience involves attempts to understand and cope with symptoms. A woman's progression through three phases which include: perceiving the health problem, learning to read the body, and negotiating the medical management of the condition enable her to establish boundaries of normality in this stage. As measures aiming to manage bodily changes fail, the woman faces the option of having a

hysterectomy and, over time, the decision to undergo this surgery is made.

In the second stage of this process, the individual engages in a struggle to minimize a sense of fragmentation and loss of control by managing her separation from significant others, and by seeking to moderate the devaluation implicit in becoming a patient. Following the surgical event, the hysterectomy patient prepares herself to face the future by observing and attempting to understand her bodily changes.

The focus of the third stage of the hysterectomy experience is to reestablish a normal life. In this stage, the woman adjusts to her bodily changes through the implementation of strategies to enhance healing. The woman's perception of a successful adjustment is contingent upon her observation of consistent healing over time, and an increased level of energy as she gradually resumes her social roles. In addition, the individual endeavors to come to terms with her surgery during this stage by measuring her assessment of her physical recovery against the physician's expert opinion; and by attempting to obtain conclusive information about the causal factors of the health problem which confirm the decision for surgery. The woman comes to terms with her illness experience and is able to resume a normal life if she perceives that she has successfully adjusted to her bodily changes, and confirmed the decision for hysterectomy.

Several differences were noted in terms of women's ability to cope with bodily changes and in their perceptions of the hysterectomy experience. The values and beliefs of significant others and health professionals, along with the social situations in which these women lived were found to enhance or impede their coping abilities, and to affect how they perceived their changing situation. In addition, these women considered the support of others to be helpful in those instances where it was conveyed with respect, and given in such a way as to recognize them as responsible individuals. The support of significant others and health professionals was noted to empower the informants when it was provided in this manner as it facilitated their endeavors to develop a sense of competence in understanding their health problem. Furthermore, it also enabled them to exercise a control

over the management of bodily changes, and to create social roles protecting and/or increasing their self-esteem. Of particular importance is the finding that a woman's high level of input during the hysterectomy decision-making moderates her sense of devaluation if she perceives her recovery as unsuccessful, and enhances her self-esteem when the recovery is viewed as successful.

Further research is required in order to establish a more complete understanding of the experience of women who undergo a hysterectomy. However, common strategies that women utilize to cope, manage, and adjust to their bodily changes were revealed in this study. From these findings, a number of propositional statements were derived and, it is hoped that these will be of assistance to other investigators.

REFERENCES

Ackner, B. (1960). Emotional aspects of hysterectomy. A follow-up study of fifty patients under the age of 40. In A. Jores & H. Freyberger (Eds.), *Advances in psychosomatic medicine* (pp. 248-252). New York: Brunner.

Alix, S. (1986). *L'hystérectomie*. Montréal: Les Éditions de L'Homme.

Ananth, J. (1983). Hysterectomy and sexual counselling. *Psychiatric Journal of the University of Ottawa, 8* (4), 213-217.

Angel, R., & Thoits, P. (1987). The impact of culture on the cognitive structure of illness. *Culture, Medicine, and Psychiatry, 11* (4), 465-494

Apple, D. (1960). How laymen define illness. *Journal of Health and Human Behavior, 1*, 219-225.

Barker, M. G. (1968). Psychiatric illness after hysterectomy. *British Medical Journal, 2*, 91-95.

Bégin, M. (1987, November). *Re-designing health care for women*. Paper presented at the CRIAW/ICREF annual meeting, Winnipeg, Man.

Belenky, M. F., Clinchy, B. M., Goldberger, N. R., & Tarule, J. M. (1986). *Women's ways of knowing: The development of self, voice, and mind.* New York: Basic Books.

Bernhard, L. (1986). Methodology issues in studies of sexuality and hysterectomy. *Journal of Sex Research, 22* (1), 108-128.

Bishop, G. D. (1987). Lay conceptions of physical symptoms. *Journal of Applied Social Psychology, 17* (2), 127-146.

Chenitz, W. C., & Swanson, J. M. (1986). *From practice to grounded theory*. Menlo Park, CA: Addison-Wesley.

Chrisman, N. J., & Kleinman, A. (1983). Popular health care, social networks, and cultural meanings: The orientation of medical anthropology. In D. Mechanic (Ed.), *Handbook of health, health care, and the health professions* (pp.569-590). New York: The Free Press.

Chynoweth, R. (1973). Psychological complications of hysterectomy. *Australian and New Zealand Journal of Psychiatry, 7*, 102-104.

Cohen, S. M., Hollingsworth, A. O., & Rubin, M. (1989). Another look at psychologic complications of hysterectomy. *Image, 21* (1), 51-53.

Cosper, B., Fuller, S. S., & Robinson, G.J. (1978). Characteristics of posthospitalization recovery following hysterectomy. *Journal of Obstetric Gynecologic and Neonatal Nursing, 7* (3), 7-11.

Crowe, M., Sunley, E. B., & Sukenik, J. D. (1984). Some common and uncommon health and medical problems. The Boston Women's Health Book Collective, *The new our bodies, ourselves* (pp.475-517). New York: Simon & Schuster.

Davis, D. L. (1984). Medical misinformation: Communication between outport Newfoundland women and their physicians. *Social Science and Medicine, 18* (3), 273-278.

Deatrick, J. A. (1984). It's their decision now: Perspectives of chronically disabled adolescents concerning surgery. *Issues in Comprehensive Pediatric Nursing, 7* (1), 17-31.

Dennerstein, L., Wood, C., & Burrows, G. D. (1977). Sexual response following hysterectomy and oophorectomy. *Obstetrics and Gynecology, 49*, 92-96.

Derogatis, L. R. (1980). Breast and gynecologic cancers: Their unique impact on body image and sexual identity in women. *Frontiers in Radiation Therapy and Oncology, 14*, 1-11.

Dicker, R. C., Greenspan, J. R., Strauss, L. T., Cowart, M. R., Sally, M. J., Peterson, H. B., DeStefano, F., Rubin, G. L., & Ory, H. W. (1982). Complications of abdominal and vaginal hysterectomy among women of reproductive age in the United States. *American Journal of Obstetrics and Gynecology, 144* (7), 841-848.

Diers, D. (1979). *Research in nursing practice*. Philadelphia: J.B. Lippincott.

Dingwall, R. (1976). *Aspects of illness*. New York: St.Martin's Press.

Donnell-Connors, D. (1980). Sickness unto death: Medicine as mythic, necrophilic and iatrogenic. *Advances in Nursing Science, 2* (3), 39-51.

Donnell-Connors, D. (1985). Women's sickness: A case of secondary gains or primary losses. *Advances in Nursing Science, 7* (3), 1-17.

Drellich, M. G., & Bieber, I. (1958). The psychologic importance of the uterus and its functions. *Journal of Nervous and Mental Disease, 126*, 322-336.

Drummond, J., & Field, P. A. (1984). Emotional and sexual sequelae following hysterectomy. *Health Care for Women International, 5*, 261-271.

Dyck, F. J., Murphy, F. A., Murphy, J. K., Road, D. A., Boyd, M. S., Osborne, E., DeVlieger, D., Korchinski, B., Ripley, C., Bromley, A. T., & Innes, P. B. (1977). Effect of surveillance on the number of hysterectomies in the province of Saskatchewan. *New England Journal of Medicine, 296* (23), 1326-1328.

Easterday, C. L., Grimes, D. A., & Riggs, J. A. (1983). Hysterectomy in the United States. *Obstetrics and Gynecology, 62* (2), 203-212.

Ehrenreich, B., & English, D. (1973a). *Complaints and disorders: The sexual politics of sickness*. New York: The Feminist Press.

Ehrenreich, B., & English, D. (1973b). *Witches, midwives, and nurses: A history of women healers* (2nd ed.). New York: The Feminist Press.

Eisenberg, L (1977). Disease and illness: Distinctions between professional and popular ideas of sickness. *Culture, Medicine, and Psychiatry, 1* (1), 9-23.

Field, P. A., & Morse, J. M. (1985). *Nursing research: The application of qualitative approaches*. London: Croom Helm.

Friedl, J. (1982). Explanatory models of black lung: Understanding the health-related behavior of appalachian coal miners. *Culture, Medicine, and Psychiatry, 6* (1), 3-10.

Fugate-Woods, N. (1982). Women's health: Perspectives for nursing research. *Nursing Clinics of North America, 17* (1), 112-119.

Gallin, R. S. (1980). Life difficulties, coping, and the use of medical services. *Culture, Medicine, and Psychiatry, 4* (3), 249-269.

Gath, D., Cooper, P., & Day, A. (1982). Hysterectomy and psychiatric disorder: Levels of psychiatric morbidity before and after hysterectomy. *British Journal of Psychiatry, 140*, 335-350.

Glaser, B. G. (1978). *Theoretical sensitivity*. Mill Valley, CA: The Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine

Gould, D., & Wilson-Barnett, J. (1985). A comparison of recovery following hysterectomy and major cardiac surgery. *Journal of Advanced Nursing, 10* (4), 315-323.

Hampton, P. T., & Tarnasky, W. G. (1974). Hysterectomy and tubal ligation: A comparison of the psychological aftermath. *American Journal of Obstetrics and Gynecology, 119*, 949-952.

Hutchinson, S. (1986). Grounded theory: The method. In P. L. Munhall & C. J. Oiler (Eds.), *Nursing research: A qualitative perspective* (pp.111-130). Norwalk, CT: Appleton-Century-Crofts.

Jackson, P. (1979). Sexual adjustment to hysterectomy and the benefits of a pamphlet for patients. *New Zealand Medical Journal, 90*, 471-472.

Kaltreider, N. B., Wallace, A., & Horowitz, M. J. (1979). A field study of the stress response syndrome: Young women after hysterectomy. *Journal of the American Medical Association, 242* (14), 1499-1503.

Katon, W., & Kleinman, A. (1981). Doctor-patient negotiation and other social science strategies in patient care. In L. Eisenberg, & A. Kleinman (Eds.), *The relevance of social science for medicine* (pp.253-279). Dordrecht, Holland: D. Reidel Publishing Company.

Kleinman, A. (1981). On illness meanings and clinical interpretation: Not 'rational man', but a rational approach to man the sufferer / man the healer [Comment]. *Culture, Medicine, and Psychiatry, 5* (4), 373-377.

Krueger, J. C., Hassell, J., Goggins, D. B., Ishimatsu, T., Pablico, M. R., & Tuttle, E. J. (1979). Relationship between nurse counseling and sexual adjustment after hysterectomy. *Nursing Research, 28* (3), 145-150.

Lalinec-Michaud, M., & Engelsmann, F. (1984). Depression and hysterectomy: A prospective study. *Psychosomatics, 25* (7), 550-558.

Lalinec-Michaud, M., & Engelsmann, F. (1985). Anxiety, fears and depression related to hysterectomy. *Canadian Journal of Psychiatry, 30*, 44-47.

Lazarus, R. S. (1974). Psychological stress and coping in adaptation and illness. *International Journal of Psychiatry in Medicine, 5* (4), 321-333.

LeBaron, S., Reyher, J., & Stack, J. M. (1985). Paternalistic vs egalitarian physician styles: The treatment of patients in crisis. *Journal of Family Practice, 21* (1), 56-62.

LeCompte, M. D., & Goetz, J. P. (1982). Problems of reliability and validity in ethnographic research. *Review of Educational Research, 52* (1), 31-60.

Lindemann, E. (1941). Observations on psychiatric sequelae to surgical operations in women. *American Journal of Psychiatry, 98*, 132-137.

Lobb, M. L., Shannon, M. C., Recer, S. L., & Allen, J. B. (1984). A behavioral technique for recovery from the psychological trauma of hysterectomy. *Perceptual and Motor Skills, 59* (2), 677-678.

Martin, E. (1987). *The woman in the body: A cultural analysis of reproduction.* Boston: Beacon Press.

Martin, R. L, Roberts, W. V., & Clayton, P. J. (1980). Psychiatric status after hysterectomy: A one-year prospective follow-up. *Journal of the American Medical Association, 244* (4), 350-353

McKinlay, J. B. (1981). Social network influences on morbid episodes and the career of help seeking. In L. Eisenberg, & A. Kleinman (Eds.), *The relevance of social science for medicine* (pp.77-107). Dordrecht, Holland: D. Reidel Publishing Company.

Meikle, S., Brody, H., & Pysh, F. (1977). An investigation into the psychological effects of hysterectomy. *Journal of Nervous and Mental Disease, 164* (1), 36-41.

Melody, G. F. (1962). Depressive reactions following hysterectomy. *American Journal of Obstetrics and Gynecology, 83* (3), 410-413.

Mishler, E. G. (1979). Meaning in context: Is there any other kind? *Harvard Educational Review, 49* (1), 1-19.

Moore, J. T., & Tolley, D. H. (1976). Depression following hysterectomy. *Psychosomatics, 17* (2), 86-89.

Moos, R. H., & Schaeffer, J. A. (Eds.). (1984). *Coping with physical illness 2: New perspectives.* New York: Plenum Medical Book.

Morgan S. (1985). *Coping with a hysterectomy* (rev. ed.). New York: New American Library.

Morse, J. M. (1986). Quantitative and qualitative research: Issues in sampling. In P. L. Chinn (Ed.), *Nursing research methodology: Issues and implementation* (pp.181-191). Rockville, MD: Aspen Press.

Nadelson, C. C., Notman, M. T., & Ellis, E. A. (1983). Psychosomatic aspects of obstetrics and gynecology. *Psychosomatics, 24* (10), 871-884.

Nichter, M. (1981). Negotiation of the illness experience: Ayurvedic therapy and the psychosocial dimension of illness. *Culture, Medicine, and Psychiatry, 5* (1), 5-24.

Patterson, R. M., & Craig, J. B. (1963). Misconceptions concerning the psychological effects of hysterectomy. *American Journal of Obstetrics and Gynecology, 85* (1), 104-111.

Rand, C. S. W., Robbins, L., & Kuldau, J. M. (1983). Stressful life events and the decision for surgery for obesity. *Psychosomatics, 24* (4), 377-384.

Richards, B. C. (1978). Hysterectomy: From women to women. *American Journal of Obstetrics and Gynecology, 131* (4), 446-452.

Richards, D. H. (1973). Depression after hysterectomy. *Lancet, 2*, 430-432.

Richards, D. H. (1974). A post-hysterectomy syndrome. *Lancet, 2*, 983-985.

Ridgeway, V., & Mathews, A. (1982). Psychological preparation for surgery: A comparison of methods. *British Journal of Clinical Psychology, 21*, 271-280.

Roos, N. P. (1984). Hysterectomies in one Canadian province: A new look at risks and benefits. *American Journal of Public Health, 74* (1), 39-46.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8* (3), 27-37.

Scheper-Hughes, N., & Lock, M. M. (1987). The mindful body: A prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly, 1* (1), 6-41.

Schön, D. A. (1983). *The reflective practitioner: How professionals think in action.* New York: Basic Books.

Seibel, M. M., Freeman, M. G., & Graves, W. L. (1980). Carcinoma of the cervix and sexual function. *Obstetrics and Gynecology, 55* (4), 484-487.

Sewell, H. H., & Edwards, D. W. (1979). Pelvic genital cancer: Body image and sexuality. *Frontiers in Radiation Therapy and Oncology, 14*, 35-41.

Shapiro, M. C., Najman, J. M., Chang, A., Keeping, J. D., Morrison, J., & Western, J. S. (1983). Information control and the exercise of power in the obstetrical encounter. *Social Science and Medicine, 17* (3), 139-146.

Simms, L. M. (1981). The grounded theory approach in nursing research. *Nursing Research, 30* (6), 356-359.

Stanfill, P. H. (1982). The psychosocial implications of hysterectomy. *Journal of Obstetric Gynecologic and Neonatal Nursing, 11* (5), 318-320.

Steele, S. J., & Goodwin, M. F. (1975). A pamphlet to answer the patient's questions before hysterectomy. *Lancet, 2*, 492-493.

Steptoe, A., Horti, J., & Stanton, S. (1986). Concern about cancer in women undergoing elective gynaecological surgery. *Social Science and Medicine, 23* (11), 1139-1145.

Stern, P. N. (1980). Grounded theory methodology: Its uses and processes. *Image, 12* (1). 20-23.

Stern, P. N., & Moxley, P. A. (1984). Qualitative research: The nurse as grounded theorist. *Health Care for Women International, 5*, 371-385.

Stern, P. N., & Pyles, S. H. (1985). Using grounded theory methodology to study women's culturally based decisions about health. *Health Care for Women International, 6* (1-3), 1-24.

Stewart, M. J. (1989). Social support: Diverse theoretical perspectives. *Social Science and Medicine, 28* (12), 1275-1282.

Szasz, T. S., & Hollender, M. H. (1956). A contribution to the philosophy of medicine: The basic models of the doctor-patient relationship. *Archives of Internal Medicine, 97*, 585-592.

Thomas, E. J. (1977). *Marital communication and decision-making: Analysis, assessment, and change*. New York: The Free Press.

Twaddle, A. C. (1981). Sickness and the sickness career: Some implications. In L. Eisenberg, & A. Kleinman (Eds.), *The relevance of social science for medicine* (pp.111-133). Dordrecht, Holland: D. Reidel Publishing Company.

Wallace, L. M. (1986). Informed consent to elective surgery: The 'therapeutic' value? *Social Science and Medicine, 22* (1), 29-33.

Webb, C. (1986). Professional and lay social support for hysterectomy patients. *Journal of Advanced Nursing, 11* (2), 167-177.

Webb, C. (1987). Defining women and their health: The case of hysterectomy. In J. Orr (Ed.), *Women's health in the community* (pp.39-56). Chichester, England: John Wiley & Sons.

Webb, C., & Wilson-Barnett, J. (1983a). Hysterectomy: A study in coping with recovery. *Journal of Advanced Nursing, 8* (4), 311-319.

Webb, C., & Wilson-Barnett, J. (1983b). Self-concept, social support and hysterectomy. *International Journal of Nursing Studies, 20* (2), 97-107.

Wijma, K., Kauer, F. M., & Janssens, J. (1984). Indications for, prevalence and implications of hysterectomy: A discussion. *Journal of Psychosomatic Obstetrics and Gynaecology, 3*, 69-77.

Wilson-Barnett, J. (1979). *Stress in hospital: Patients' psychological reactions to illness and health care*. New York: Churchill Livingstone.

Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation, 21* (6), 234-239.

Zervos, S. K., & Papaloucas, A. C. (1972). Psychosomatic disturbances following hysterectomy performed at a premenopausal age. *International Surgery, 57* (10), 802-804.

Zola, I. K. (1966). Culture and symptoms: An analysis of patients' presenting complaints. *American Sociological Review, 31*, 615-630.

Zola, I. K. (1981). Structural constraints in the doctor-patient relationship: The case of non-compliance. In L. Eisenberg, & A. Kleinman (Eds.), *The relevance of social science for medicine* (pp.241-252). Dordrecht, Holland: D. Reidel Publishing Company.

Zussman, L., Zussman, S., Sunley, R., & Bjornson, E. (1981). Sexual response after hysterectomy-oophorectomy: Recent studies and reconsideration of psychogenesis. *American Journal of Obstetrics and Gynecology, 140* (7), 725-729.

APPENDIX

The Experience of Women who Undergo Hysterectomy

Informant Consent Form

Marie-Andrée Chassé (MN Candidate)
11247 - 76 Avenue
Edmonton, Alberta, T6G 0K2
Tel: 437-2876

Dr. Janice Morse (Supervisor)
Professor, Faculty of Nursing
University of Alberta
Edmonton, Alberta, T6G 2G3

This is to certify that I, _____ have given consent to participate in a research project conducted by Marie-Andrée Chassé, a Master's student in nursing at the University of Alberta. It is my understanding that I will be interviewed by Ms Chassé in order to enable her to obtain information concerning my experience of a hysterectomy.

I also understand that I will be interviewed at one month and again at three months postoperatively, for approximately one hour each time. The interviews will be tape-recorded and transcribed. My name will not appear in any research report and, the tape-recorded interviews will be number coded and kept safely to preserve my anonymity. I am free to terminate any interview at any time, free to refuse to answer any questions and to withdraw from the project at any time without negative consequences. Finally, I understand that tapes will be erased and transcriptions shredded after completion of the project.

Participant Investigator

Signature:_____ _____

Date:_____